

# **AMERICAN BRAIN FOUNDATION**

Governance Committee January 25, 2021 9:00am CST Video Call

Attendees:	Shafali Jeste, MD, Chair; Susan Schneider Williams, BFA; Frances Jensen, MD; Kevin Goodno; David Dodick, MD; Mary Post
Staff	Jane Ransom, ED; Mary Post, CEO; Kim Howard

	AGENDA ITEM *Indicates Board Action Needed	PRESENTED BY
9:00	Call to Order and Introductions	Shafali Jeste, MD, Chair
9:00	Approval of the December 21, 2020 Minutes	Shafali Jeste, MD, Chair
9:05	2021 Goals  1. Recruit 4 board members for terms beginning 1/1/22 a. 3 non-neurologists b. 1 neurologist  2. Renew board members eligible for 2 <sup>nd</sup> and 3 <sup>rd</sup> terms 3. Recommend Slate of Officers for terms beginning 1/1/22 4. Create recommendation re Advisory/Alumni Council	Jane Ransom
9:20	Short-listed candidates  Public Candidate List JoAnne Berger Sweeney (Dr. Frances Jensen) Sanjay Gupta (Dr. Ron Petersen) Mayim Bialik (David Eagleman) Susan Sarofim (Susan Williams) *not until 1/1/22 Dr. Keith Black (Dr. David Dodick  Neurologits Candidate List Alyx Porter, MD (added 1/1/2021) Dr. Merit Cudkowicz (Dr. Robert Griggs) Dr. John Morris (Dr. Robert Griggs)	Jane Ransom
9:25	Review and approve officers survey	Jane Ransom
9:30	Meeting adjourn	Shafali Jeste, MD, Chair

## Other Materials:

- Draft Minutes of December 21, 2020 (pg. 3)
  Board Term Expiration Roster (pg. 6)
  Draft Officers Survey (pg. 7)

- Board Recruitment Matrix (pg. 16)
- 2020 Candidates List (pg. 18)
- 2021 Governance Committee Meeting Schedule (pg. 51)



# American Brain Foundation Governance Committee Meeting December 21, 2020 9:00 a.m. CT Video Conference Call

In attendance: Kevin Goodno, Chair; Susan Schneider Williams, BFA; Frances Jensen, MD Staff: Jane Ransom, ED; Kim Howard

The meeting was called to order at 9:03 a.m. CT by Kevin Goodno, Chair.

The minutes of September 21, 2020 were approved unanimously.

**Board Recruitment Update (Jane Ransom)** 

# Public Candidate List

- JoAnne Berger Sweeney Dr. Jensen and Jane Ransom have spoken with Ms.
  Sweeny. She is interested in the foundation, but she is over-committed right now. She
  would consider joining the board in a year or two. She would be happy to come to a
  future board meeting to discuss her experiences as a neuroscientist and college
  president, and the needs she sees around diversity and advocacy. She is an interested
  prospect that we will continue to nurture.
- Sanjay Gupta We plan to give him his award first at Commitment to Cures and then reach out to him.
- Mayim Bialik Waiting to hear back from Mr. Eagleman, he was going to reach out to Ms. Bialik and we have not had an update.
- Susan Sarofim She is still very interested but not until 2022.
- Dr. Keith Black Dr. Dock has sent multiple messages and has still not heard back from him.

New people mentioned for consideration include Jeff Bezos ex-wife MacKenzie Scott and Mark Zuckerberg's wife Priscilla Chan.

### **Neurologist Candidate List**

- Dr. Merit Cudkowicz & Dr. John Morris We are not actively recruiting them but
  wanted to note they will be coming off the Research Advisory Committee at the end of
  this year. They have been top contributors to the RAC so rather than lose them we might
  want to consider one or both joining the Board.
- Alyx Porter Dr. Porter was the first African American female neuro-oncologist in the US. She is a former student of Dr. Dodick's and she works at the Mayo Clinic. Ms. Porter

also directs a non-profit, called Elevate MD, that medical students of color with scholarships. She would be a great addition to the board and has already agreed to be on the board on a recent call with Dr. Dodick. Dr. Jensen mentioned Dr. Porter's background fits perfectly with our efforts and pursuits around glioblastoma.

MOTION: Recommendation be made to the Board to add Dr. Alyx Porter effective January 1, 2021 via email vote to replace Sharon Klein. Motion approved unanimously.

Mr. Goodno noted that when Dr. Sirven departs in April we will want to replace him with a public candidate since Dr. Porter was a neurologist candidate. We do not have to fill them right away; we can take our time and make sure we get the right candidates.

Research Advisory Committee Update (David Dodick, MD) As a result of two special Research Strategy meetings, there is agreement on the following:

The Research Advisory Committee will make recommendations to the Board regarding research priorities of the ABF, including which research projects that should be funded by the Foundation. Collaborating and aligning with the research program of the AAN is a priority. Focused activities will include the following:

- Expand ABF's portfolio of training scholarships for early career researchers
- Recommend special research funding initiatives related to specific diseases or disease areas
- Develop programs that advance research in health disparities
- Collaborate with AAN's Science Committee

Nothing has changed related to membership and terms. Mr. Goodno confirmed that the Board Chair has the authority to appoint the Chair and members of the RAC.

Research Advisory Committee Appointments (Jane Ransom) Three members of the RAC have agreed to renew for a second term beginning January 1, 2021:

- Phyllis Zee, MD
- Jose Cavazos, MD
- James Grotta, MD

Six of our RAC members are term limiting out at the end of 2021. The committee discussed adding six people to the RAC for terms beginning 1/1/21 to prepare for those departures. It was suggested to have more members of the Board be on the RAC. There was some concern about such a large group until Ms. Ransom suggested creating sub-committees to address each area of the focused activities defined above. We need diversity in expertise (specialty) and we also need more women. To achieve more diversity, we can consider future candidates that are more mid-career.

The Governance Committee recommended seven appointments to the RAC to Board Chair David Dodick, to begin their terms on 1/1/21:

• Bruce Ovbiagele, MD, MAS

- Na Tosha N. Gatson, MD, PhD
- Gordon Smith, MD, PhD
- Jacqueline French, MD
- Jose Biller, MD
- Ronald Petersen, PhD, MD
- Reisa Sperling, MD

**2021 Governance Committee Chair, Shafali Jeste (David Dodick, MD)** Dr. Shafali Jeste has agreed to become the Governance Chair for 2021.

The Governance Committee thanked Kevin Goodno for his leadership of the Governance Committee for the last six years, crediting him with building up the great board we have now.

Meeting Adjourned 9:42 a.m. CT



# Board of Directors - Term Expirations

	Director Terms			
	End 1st Term	End 2nd Term	End 3rd Term	Extension
Dodick, David	12/31/2019	12/31/2021		
Goodno, Kevin	2013	2015	12/31/2017	Yes
Schneider Williams, Susan	12/31/2017	12/31/2019	12/31/2021	
Essey, Jim	12/31/2019	12/31/2021		
Jeste, Shafali	12/31/2019	12/31/2021		
Eagleman, David	12/31/2019	12/31/2021		
Erwin, James	12/31/2021			
French, Jacqueline	12/31/2021			
Gasby, Dan	12/31/2018	12/31/2020	12/31/2022	
Grotta, James	12/31/2019	12/31/2021		
Jensen, Frances	12/31/2021			
Lenail, Ben	12/31/2022			
McCain, Cindy	12/31/2021			
Miller, Suzanne	12/31/2020	12/31/2022		
Petersen, Ronald	12/31/2020	12/31/2022		
Porter, Alyx	12/31/2022			
Sansiveri, Sean	12/31/2021			
Shenkman, Martin	12/31/2017	12/31/2019	12/31/2021	
Sirven, Joseph	12/31/2021			
Ex Officio Voting				
Stevens, James	AAN President			
Griggs, Robert	RAC Chair			
Ex Officio Non-Voting				
Ransom, Jane	ABF ED			
Post, Mary	AAN ED/CEO			
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Officer Terms			
End 1st	Eligible for 2nd	End 2nd	
12/31/2021	YES		
12/31/2021	NO		
12/31/2019	YES	12/31/2021	
12/31/2021	YES		
12/31/2021	YES		
	End 1st  12/31/2021 12/31/2021 12/31/2019 12/31/2021	End 1st Eligible for 2nd  12/31/2021 YES  12/31/2021 NO  12/31/2019 YES  12/31/2021 YES	



# **ABF Board Office Leadership Survey (2022)**

This is a survey of the American Brain Foundation Board members to gather insights about potential candidates for the slate of officers that will begin serving as our leadership effective January 1, 2022. This Survey is confidential, with the results to be seen only by the American Brain Foundation's Governance Committee.

\*Survey questions are based on characteristics identified by BoardSource and the Center on Philanthropy at Indiana University.

# 1. Personal Commitment to the American Brain Foundation

In the nonprofit sector, personal commitment is best defined as "passion for the mission that is backed up by the devotion of time, energy, and funds." It includes a "willingness to ask others for financial commitment, too."

Thinking about the Board members who could be eligible for an officer position in 2022, please indicate **three** who, in your opinion, best meet this definition.

David Dodick, MD, FAAN	Shafali Jeste, MD
David Eagleman, PhD	Ben Lenail
Jim Essey	Cindy McCain
Jimmy Erwin	Suzanne Miller
Jackie French, MD	Ron Petersen, PhD, MD, FAAN
Dan Gasby	Alyx Porter, MD
Kevin Goodno	Sean Sansiveri
Robert (Berch) Griggs, MD	Martin Shenkman, CPA
Jim Grotta, MD	Joe Sirven, MD
Frances Jensen, MD, FACP, FAAN	Susan Schneider Williams, BFA
Additional Comments:	

2. Strategist			
Sees the big picture. Able to set goals, determine actions to achieve goals, and mobilize resources to			
execute action. Makes sure strong strategic plan	execute action. Makes sure strong strategic plan is in place which is followed and monitored.		
Thinking about the Board members who coul	ld be eligible for an officer position in 2022, please indicate		
three who, in your opinion, best meet this definit	tion.		
David Dodick, MD	Shafali Jeste, MD		
David Eagleman, PhD	Ben Lenail		
Jimmy Erwin	Cindy McCain		
Jim Essey	Suzanne Miller		
Jackie French, MD	Ron Petersen, PhD, MD, FAAN		
Dan Gasby	Alyx Porter, MD		
Kevin Goodno	Sean Sansiveri		
Robert (Berch) Griggs, MD	Martin Shenkman, CPA		
Jim Grotta, MD	Joe Sirven, MD		
Frances Jensen, MD, FACP, FAAN	Susan Schneider Williams, BFA		
Additional Comments:			

3. Governance Knowledge & Experience			
Knowledgeable about the organization and governance best practices. An effective facilitator who can			
create a purposeful agenda with the ED, run a productive meeting, engage board members in deliberation			
and control dominating or out-of-line behavior during meetings.			
Thinking about the Board members who could be eligible for an officer position in 2022, please indicate			
three who, in your opinion, best meet this definition.			
David Dodick, MD	Shafali Jeste, MD		
David Eagleman, PhD	Ben Lenail		

ree who, in your opinion, best meet this definition.  David Dodick, MD  David Eagleman, PhD  Ben Lenail  Cindy McCain  Suzanne Miller  Jackie French, MD  Ron Petersen, PhD, MD, FAAN  Alyx Porter, MD  Sean Sansiveri  Robert (Berch) Griggs, MD  Martin Shenkman, CPA  Jim Grotta, MD  Frances Jensen, MD, FACP, FAAN  Additional Comments:
David Eagleman, PhD  Ben Lenail  Cindy McCain  Jim Essey  Suzanne Miller  Ron Petersen, PhD, MD, FAAN  Dan Gasby  Alyx Porter, MD  Kevin Goodno  Sean Sansiveri  Robert (Berch) Griggs, MD  Martin Shenkman, CPA  Jim Grotta, MD  Frances Jensen, MD, FACP, FAAN  Susan Schneider Williams, BFA
Jimmy Erwin  Jim Essey  Suzanne Miller  Ron Petersen, PhD, MD, FAAN  Dan Gasby  Alyx Porter, MD  Kevin Goodno  Sean Sansiveri  Robert (Berch) Griggs, MD  Martin Shenkman, CPA  Jim Grotta, MD  Susan Schneider Williams, BFA
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Jackie French, MD Ron Petersen, PhD, MD, FAAN Alyx Porter, MD Kevin Goodno Sean Sansiveri Robert (Berch) Griggs, MD Martin Shenkman, CPA Jim Grotta, MD Joe Sirven, MD Frances Jensen, MD, FACP, FAAN Susan Schneider Williams, BFA
Dan Gasby  Alyx Porter, MD  Kevin Goodno  Sean Sansiveri  Martin Shenkman, CPA  Jim Grotta, MD  Joe Sirven, MD  Frances Jensen, MD, FACP, FAAN  Susan Schneider Williams, BFA
Kevin Goodno Sean Sansiveri Martin Shenkman, CPA Jim Grotta, MD Joe Sirven, MD Frances Jensen, MD, FACP, FAAN Susan Schneider Williams, BFA
Robert (Berch) Griggs, MD  Martin Shenkman, CPA  Jim Grotta, MD  Joe Sirven, MD  Frances Jensen, MD, FACP, FAAN  Susan Schneider Williams, BFA
Jim Grotta, MD Joe Sirven, MD  Frances Jensen, MD, FACP, FAAN Susan Schneider Williams, BFA
Frances Jensen, MD, FACP, FAAN Susan Schneider Williams, BFA
dditional Comments:

4. Works effectively with Executive D	Director
Supports and consults with the ED in a mutu	al pursuit to advance the mission of the organization through
open, regular communication. Comfortable with	roles where the Board sets high-level policy and strategy,
whereas the ED manages implementation and o	pperational activities.
Thinking about the Board members who cou	ld be eligible for an officer position in 2022, please indicate
three who, in your opinion, best meet this defini	tion.
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Jim Grotta, MD	Joe Sirven, MD
Frances Jensen, MD, FACP, FAAN	Susan Schneider Williams, BFA
Additional Comments:	

5. Great Relationship Manager		
Able to blend diverse personalities and backgrounds together in order to get things done and keep Board		
members accountable and working together.		
Thinking about the Board members who could be	be eligible for an officer position in 2022, please indicate	
three who, in your opinion, best meet this definition	n.	
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Kevin Goodno	Sean Sansiveri	
Robert (Berch) Griggs, MD	Martin Shenkman, CPA	
Jim Grotta, MD	Joe Sirven, MD	
Frances Jensen, MD, FACP, FAAN	Susan Schneider Williams, BFA	
Additional Comments:		

6. Results Oriented		
Keeps the Board's orientation focused on achieving results in alignment with the strategic plan.		
Thinking about the Board members who could be eligible for an officer position in 2022, please indicate		
three who, in your opinion, best meet this definiti	ion.	
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Jim Essey	Suzanne Miller	
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Kevin Goodno	Sean Sansiveri	
Robert (Berch) Griggs, MD	Martin Shenkman, CPA	
Jim Grotta, MD	Joe Sirven, MD	
Frances Jensen, MD, FACP, FAAN	Susan Schneider Williams, BFA	

7. Great Connections	
Knows not only the most people, but the "right"	people to help at any time or place.
Thinking about the Board members who could b	be eligible for an officer position in 2022, please indicate <b>three</b>
who, in your opinion, best meet this definition.	
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Robert (Berch) Griggs, MD	Martin Shenkman, CPA
Jim Grotta, MD	Joe Sirven, MD
Frances Jensen, MD, FACP, FAAN	Susan Schneider Williams, BFA
Additional Comments:	
L	

8. Not Over-Committed	
Able to devote time and attention to the Found	dation. Not so over-committed that focus on the organization
is diluted.	
Thinking about the Board members who could	d be eligible for an officer position in 2022, please indicate
three who, in your opinion, best meet this definiti	ion.
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Jim Grotta, MD	Joe Sirven, MD
Frances Jensen, MD, FACP, FAAN	Susan Schneider Williams, BFA

	t key tasks completed and makes meetings fun.
Thinking about the Board members who cou	ıld be eligible for an officer position in 2022, please indica
nree who, in your opinion, best meet this defin	ition.
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Kevin Goodno	Sean Sansiveri
Robert (Berch) Griggs, MD	Martin Shenkman, CPA
Jim Grotta, MD	Joe Sirven, MD
	Susan Schneider Williams, BFA  ht or comments?
Additional Comments:	
Additional Comments:  Do you have any other thoug	

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<b>Board Members</b>	Sec	ctor		Skill	/Exp	erie	ence/	⁄Ехр	ertise	9		Ad	cess	/Con	necti	ons		Addit Attril	tional butes			Diversity		Years on Board	Voting Member	Committee (s)	Office
	Public	AAN Member	Marketing	Financial Planning/Management	Organizational Management	H.R. Management	Fundraising	Legal	Leadership Development	Neuroscience/Neurology	Foundations	Affluent Individuals	Business/Corporations	Politics/Government	Religious Community	Volunteer Health Organizations	Grassroots Constitutents	Major Donor giving capacity	Connected to mission/vision	Location	Gender	Race	Age Range				
	Х		Х							Х	Х	Х	Х						х	CA	М	Caucasian/ White	40-50	0	Х		Director
	Х			Х	х	Х						Х	Х			Х		Х	х	NY	М	Caucasian/ White	60-69	0	Х		Director
	Х		Х				х				Х	х	х	Х		Х		Х	х	NY	М	African American/B lack	60-69	1	Х	Governance	Director
	х		х	х	х			х			х		х	х		х		х	х	MN	М	Caucasian/ White	50-59	7	x	Governance; Strategic Planning; Executive	Chair
		Х			х		х			х			Х					х	х	NY	М	Caucasian/ White	70-79	7	X	Research Advisory	Vice Chair
		Х								Х	Х					Х			Х	CA	F	Asian	40-49	0	Х		Director
		Х					х			х								Х	Х	NY	М	Caucasian/ White	60-69	5	х	Compensation	Treasurer
		x					x			х						х		х	x	РА	М	African American/ Black	60-69	0	х		Director
		х																х	х	CA	М	Caucasian/ White	60-69	7	х	Governance	Past Chair
		х				х				х	Х	х				Х		х	Х	CA	М	Caucasian/ White	60-69	2	x	Governance	Director

	х	х	Х	х	X	Х			Х	Х	х	х		X		Х	х	Х	CA	М	Caucasian/ White	50-59	5	X	Strategic Planning	Director
	х			х				х	х	х					х		х	х	FL	М	Caucasian/ White	50-59	1	l X	Research Advisory	Director
Х		Х	х				х				х						X	х	NJ	Μ	Other	50-59	2	X	Strategic Planning	Director
	х							х	х								х	х	MD	F	Caucasian/ White	60-69	5	X	Strategic Planning	Director
	х								х						х		х	х	ΑZ	М	Other	50-59	2	ı x	Commitment to Cures	Ex Officio Designee
	х								х		х					х	х	х	UT	М	Caucasian/ White	40-49	5	ı x	Strategic Planning	Secretary
x																	x	x	MN	F	Caucasian/ White	60-69	2		Governance; Strategic Planning; Research Advisory	Ex Officio
х				х	х			х		х	х		х				х	Х	MN	F	Caucasian/ White	60-69	7		Governance	Ex Officio
х		х				х					х						х	Х	MN	М	Caucasian/ White	30-39	2	X	Strategic Planning	Director
Х		х								х	х				х			х	CA	F	Caucasian/ White	50-59	2	l X	Commitment to Cures	Director



# **Board Recruitment Survey Results**

# **PUBLIC CANDIDATES (Non-Neurologist Candidates)**

Name	Recommended By	Page
ALFRED QUINONES-HINOJOSA	JOE SIRVEN	2
MONIKA JONES	LIZ SCHREIBER	3
STEVEN L. ROBERDS	LIZ SCHREIBER	5
SUSAN SAROFIM	DAVID DODICK & JANE RANSOM	6
CONDOLEEZZA RICE	DAVID DODICK	7
COLIN POWELL	DAVID DODICK	8
MIKE HANYES	DAVID DODICK	9
GLENNA STEELE	DARRYL DE VINO	11
LEN SCHLEIFER	UNKNOWN	12
FATEMA "TEMA" BURKEY	JANE RANSOM	14
NEAL KASSELL, MD	RICHARD SATAVA	15
JOANNE BERGER-SWEENEY	JANE RANSOM	16
SANJAY GUPTA	DAVID DODICK	17
MAYIM BIALIK	DAVID DODICK	20
CHRISTY JAGDFELD	SELF NOMINATED	22

# **NEUROLOGIST CANDIDATES**

Name	Recommended By	Page
CHRISTIANNE HECK, MD	JOE SIRVEN	23
MATTHEW STERN, MD	JOE SIRVEN	24
DIMITRI KRAINC, MD, PhD	FRANCES JENSEN	25
NAVAZ KARANJIA, MD	HE HINSON	26
ROBERT GROSS, MD, PhD	RALPH JOZEFOWICZ	27
KEITH BLACK	DAVID DODICK	29
CARMEL ARMON, MD	SELF NOMINATED	31
MERIT CUDKOWICZ, MD, MSc	JANE RANSOM	32
JOHN MORRIS, MD	JANE RANSOM	33

# **ALFREDO QUINONES-HINOJOSA**

Neurosurgeon, Author & Researcher - Chair of Neurosurgery at Mayo Clinic Florida \*recommended by Joe Sirven

Bio Links: <a href="https://www.mayoclinic.org/biographies/quinones-hinojosa-alfredo-m-d/bio-20238939">https://www.mayoclinic.org/biographies/quinones-hinojosa-alfredo-m-d/bio-20238939</a> & https://en.wikipedia.org/wiki/Alfredo Qui%C3%B1ones-Hinojosa

Q1	
First suggestion for a public board member (non-neurolog	ist):
Name:	Dr. Quinones- Hinojosa
Reason for recommendation:	Neurosurgeon
Contact information:	Quinones-Hinojosa.Alfredo@mayo.edu
Additional comments:	Chair of Neurosurgery and on Mayo Board and well known in Latin America
Q2	Highly social ,
Please indicate which of the following characteristics,	Excellent communicator,
experiences, skills, expertise, or locations apply to your first public member recommendation:	Diversity,
	Major donor capacity,
	Connected to the mission/vision of ABF

Alfredo Quinones-Hinojosa, M.D., is a consultant and serves as chair of the Department of Neurologic Surgery at Mayo Clinic's campus in Florida, and he is recognized with the distinction of a named professorship, the William J. and Charles H. Mayo Professorship. His clinical focus includes:

- Surgical treatment of primary and metastatic brain tumors with emphasis in motor and speech mapping during surgery
- Pituitary tumors and skull base tumors using transsphenoidal endonasal and minimally invasive approaches
- Providing personalized medicine to improve patient outcomes

In addition to his clinical activities, Dr. Quinones-Hinojosa leads NIH-funded research to find a cure for brain cancer. His cutting-edge research focuses on brain tumors and cell migration, health care disparities and clinical outcomes for neurosurgical patients in which the operating room is used as an extension for his research scenario. He has authored numerous high-impact scientific journal articles, chapters, abstracts and books. Dr. Quinones-Hinojosa also continues to provide mentorship to residents, graduate students and fellows.

**Clinical -** Practice focuses on the surgical treatment of primary and metastatic brain tumors, with an emphasis on motor and speech mapping during surgery and in the treatment of patients with pituitary tumors and minimal invasive approaches of skull base tumors

**Research** - Research focuses on brain tumors and stem cell migration, healthcare disparities for minorities and clinical outcomes for neurosurgical patients

Major research accomplishments include:

- Elucidating mechanisms by which brain tumors migrate
- Integrating the use of mesenchymal stem cells into local treatment of solid tumors
- Concomitant use of nanotechnology and focal beam radiotherapy in the systemic treatment of solid tumors
- Development of new imaging software to help identify areas within solid tumors with the greatest malignant potential
- Development of innovative, minimally invasive approaches to brain tumor resection

# **MONIKA JONES**

Visionary Founder & CEO of The Brain Recovery Project (Childhood Epilepsy Surgery Foundation) \*recommended by Liz Schreiber – Epilepsy Foundation

Bio Link: <a href="https://www.brainrecoveryproject.org/monika-jones-jd-%E2%80%A2-visionary-founder-and-ceo/">https://www.brainrecoveryproject.org/monika-jones-jd-%E2%80%A2-visionary-founder-and-ceo/</a>

Q1

First suggestion for a public board member (non-neurologist):

Name: Monika Jones, JD

Relationship (if any): member of Rare Epilepsy Network (REN)

Contact information: info@brainrecoveryproject.org

Additional comments: parent of child with rare epilepsy; founder & CEO of The

**Brain Recovery Project** 

https://www.brainrecoveryproject.org/monika-jones-jd-

%E2%80%A2-visionary-founder-and-ceo/

Q2

Please indicate which of the following characteristics, experiences, skills, expertise, or locations apply to your first public member recommendation:

Excellent communicator,

Access/connections to affluent individuals,

Access/connections to corporations,

Access/connections to foundations,

Located in a city of high-wealth concentration (i.e. New York, San Francisco, LA, Chicago, DC, Houston, Dallas,

Atlanta, Seattle, San Diego, or Boston)

Monika Jones, JD, Visionary Founder & CEO of The Brain Recovery Project (Childhood Epilepsy Surgery Foundation). Monika's first son, Henry, was born with total <a href="hemimegalencephaly">hemimegalencephaly</a> – a rare unilateral brain malformation which caused him to have hundreds of seizures per day shortly after birth. The seizures included <a href="infantile spasms">infantile spasms</a>, a catastrophic epilepsy which can result in profound intellectual and <a href="montor">motor</a> impairment if not stopped early. Despite a cocktail of five anti-epileptic medications, Henry went into status epilepticus at three months old and was put into a coma to stop the infantile spasms and other seizures.

Henry required a <u>modified lateral hemispherotomy</u> at three months old to stop his seizures, which unfortunately returned a year later. Despite a revision surgery, his seizures returned again, requiring a third surgery to convert to a true anatomical hemispherectomy. He has struggled with chronic hydrocephalus caused by the first surgery, required five ventriculoperitoneal shunt surgeries, multiple <u>orthopedic</u> procedures, and other challenges.

Frustrated by the lack of research to help them understand how to help their son, Monika and her husband <u>Brad Jones</u> originally founded The Brain Recovery Project to initiate and fund research to better understand neurorehabilitation after hemispherectomy surgery; however, as an active member of several social media communities for families of children with intractable epilepsy who require brain surgery, she quickly learned how underserved children are after having brain surgery to stop seizures. At her behest, the board of directors in 2017 agreed to expand the organization's reach to include all epilepsy surgeries, focusing on helping families understand when it's time to consider epilepsy surgery, and offering a host of programs post-operatively.

In 2018 and <u>2019</u>, Ms. Jones was nominated by her peers as a <u>Rare Champion of Hope</u>, an award given by <u>Global Genes</u> to honor a person's notable efforts in rare disease advocacy.

Ms. Jones is the principal investigator of the <u>Global Pediatric Epilepsy Surgery Registry</u> – the first registry to track functional outcomes after epilepsy surgery. She was the project lead for the innovative meeting <u>Functional Outcomes</u> <u>After Large Resective and Disconnective Epilepsy Surgeries: Identifying Gaps and Setting Patient Centered Outcomes Research Priorities</u> funded in large part by an almost \$50,000 <u>Eugene Washington Engagement Award</u> from the <u>Patient Center Outcomes Research Institute</u>. In 2014, she was the principal investigator of the scientific workshop on brain <u>plasticity</u>, hemispheric specialization, and neurorehabilitation after cerebral hemispherectomy, funded by a <u>R13 grant</u> from the National Institutes of Health.

#### **MONICA JONES - PAGE 2**

She is a grant reviewer for the My Brain Map initiative for the Epilepsy Foundation's Epilepsy Innovation Institute to fund pilot studies that would propose novel exploratory ways to model seizure propagation in a personalized brain network model. She serves on the Rare Epilepsies Network's steering committee, the Epilepsy Leadership Council's NINDS Epilepsy Benchmarks Stewards Workgroup for 2020, and represents the organization as part of the Child Neurology Foundation's Infantile Spasms Action Network. In addition, she represents the organization as part of the Epilepsy Learning Healthcare System's Community Engagement Core. She is

also a member of the Cortical Vision Impairment CoLab convened by <u>Perkins School for the Blind</u>, a small collaborative working group of researchers, educators, and clinicians working to improve the diagnosis, treatment, and education of children with cerebral vision impairments. Locally, she is a member of the UCLA Department of Neurosurgery's <u>Patient Advisory Council</u>.

For most of her professional career, Monika was a litigator representing corporations in various matters, including lawsuits brought by employees, insurance coverage disputes, trademark infringement, or other contractual disputes. She has served as assistant general counsel of Luminent, Inc., an optical component manufacturer, general counsel of Brown and Riding Insurance Services, a national wholesale insurance broker, and then as a vice president of Brown and Riding's casualty division. She abandoned her legal career in 2011 after founding the organization.

She is a graduate University of California at Los Angeles and received her juris doctorate from the University of Southern California. Although no longer practicing law, Monika was recently elected to the board of directors of the Council of Parent and Attorney Advocates, the only national organization for parents and attorneys who represent children with special education needs. There, she serves as co-chair of the Parent Committee. She is a founding board member of Watkins VITAL Care Program, an innovative new program that offers an educational environment for adults with moderate-to-severe autism who have aged out of the school system. She has served on the board of Portals, one of the oldest and largest mental health organizations in Los Angeles which offers mental health services in Central and South Los Angeles.

# STEVEN L. ROBERDS

Chief Scientific Officer at Tuberous Sclerosis Alliance \*recommended by Liz Schreiber – Epilepsy Foundation

# Bio Link: https://www.tsalliance.org/our-team/steven-l-roberds-phd/

Q3

Second suggestion for a public board member (non-neurologist):

Name: Steven L. Roberds, PhD

Relationship (if any): member of REN and on REN Professional Advisory

**Board** 

Contact information: sroberds@tsalliance.org

Additional comments: CSO of TS Alliance https://www.tsalliance.org/about-

us/our-team/; Pharm Co connections

Q4 Excellent communicator,

Please indicate which of the following characteristics, experiences, skills, expertise, or locations apply to your

second public member recommendation:

Access/connections to affluent individuals,

Access/connections to corporations,

Access/connections to foundations

Steven L Roberds, PhD, Chief Scientific Officer at Tuberous Sclerosis Alliance. Steve joined the TS Alliance staff in 2011 as Chief Scientific Officer. In this role, Steve leads the development and execution of the TS Alliance's research strategy through partnerships and conversations with all stakeholders, including individuals and families affected by TSC, basic and clinical researchers, healthcare providers, government agencies involved in medical research, and other non-profit organizations. In 2012, Steve led the implementation of the first TSC Clinical Consensus Conference since 1998.

In 2015, he worked with program officers at the National Institutes of Health to design and carry out a workshop to update the TSC research strategy for the next ten years. To move this updated strategy forward, Steve drove the creation of two TS Alliance-led collaborative projects: the TSC Preclinical Consortium to accelerate testing of potential new treatments and the TSC Biosample Repository to collect and share biosamples from individuals enrolled in the TSC Natural History Database.

Steve was awarded his PhD in Pharmacology from Vanderbilt University in 1992, after which he was introduced to rare disease research as a postdoctoral fellow at the University of Iowa studying the biology and genetics of muscular dystrophies. He then began a 16-year research career in the pharmaceutical industry.

Immediately prior to joining the TS Alliance, Steve was an Associate Research Fellow and project leader responsible for driving global project teams toward new human proof-of-concept studies to repurpose Pfizer compounds for new indications.

Steve has three grown children and loves exploring all the history, food, and music the Washington, DC area has to offer with his wife Mary.

# SUSAN SAROFIM

Founder of Brooke Staffing & Co-founder TEACH (To Educate All Children) \*recommended by Dr. David Dodick & Jane Ransom

Bio/Info Links: <a href="https://toeducateallchildren.org/about-2/co-founders/">https://toeducateallchildren.org/about-2/co-founders/</a> & <a href="https://www.bizjournals.com/houston/news/2018/09/14/hbj-announces-lifetime-achievement-honoree-for.html">https://www.bizjournals.com/houston/news/2018/09/14/hbj-announces-lifetime-achievement-honoree-for.html</a>

Susan Sarofim founded Brooke Staffing Cos. in 1989 in New Orleans. She relocated the headquarters to Houston in 2005 after the wake of Hurricane Katrina. Also in Houston, she co-founded TEACH, an organization that provides HISD educators the skills for them to teach at-risk students. Susan has focused most of her business knowledge and capabilities on education efforts, starting as a speaker in the New Orleans public school system. She is a founding member of Each One Save One, a mentoring program in New Orleans.

More recently, Sarofim was the chair of the Memorial Hermann Foundation board between 2015 and 2017. She is also the owner and CEO of New Orleans Auction Galleries.

Susan Sarofim is married to Fayez Sarofim who is the heir to the Sarofim family fortune, fund manager for a number of <u>Dreyfus family</u> stock funds, an original and second largest shareholder of <u>Kinder Morgan</u> (NYSE: KMI) and part owner of the <u>NFL</u> team <u>Houston Texans</u>; ranked 5th Most Valuable <u>NFL</u> team worth \$1.85 billion. With an estimated current net worth of \$1.91 billion, Sarofim is ranked by <u>Forbes</u> as the <u>847-richest person in the world</u>, in 2015. His investment firms oversee over \$30 billion in assets.

Susan and her husband, Fayez S. Sarofim, have made considerable contributions to several Houston nonprofit institutions. In February, their \$25 million donation was formally announced to the Memorial Hermann Health System's new Texas Medical Center tower. They also gave \$70 million to the Museum of Fine Arts Houston in 2015 for the funding of a new campus in their namesake, the Susan and Fayez S. Sarofim Campus.

# **CONDOLEEZZA RICE**

Political Scientist, Diplomat, Civil Servant & Professor \*recommended by Dr. David Dodick

# Bio Link: <a href="https://en.wikipedia.org/wiki/Condoleezza">https://en.wikipedia.org/wiki/Condoleezza</a> Rice

01		

Major donor capacity

Çi	d was walk and (many practical artists).
First suggestion for a public board	member (non-neurologist):
Name:	Condoleezza Rice
Reason for recommendation:	Enormous influence and capacity to grow our donor base
Relationship (if any):	I don't but another of our board members may.
Q2	
Please indicate which of the follow member recommendation:	ving characteristics, experiences, skills, expertise, or locations apply to your first public
Excellent communicator	
Access/connections to affluent individu	ials
Access/connections to corporations	
Access/connections to foundations	
Diversity	

Condoleezza "Condi" Rice is an American <u>political scientist</u>, diplomat, civil servant, and professor who served as the <u>66th United States Secretary of State</u> from 2005 to 2009. Rice was the first female African-American Secretary of State, as well as the <u>second African-American Secretary of State</u> (after <u>Colin Powell</u>), and the <u>second female Secretary of State</u> (after <u>Madeleine Albright</u>). Rice was President <u>George W. Bush</u>'s <u>National Security Advisor</u> from 2001 to 2005, making her the first woman to serve in that position.

Rice was born in Birmingham, Alabama, and grew up while the South was racially segregated. She obtained her bachelor's degree from the <u>University of Denver</u> and her master's degree in political science from the <u>University of Notre Dame</u>. In 1981 she received a PhD from the School of International Studies at the University of Denver. [1][2] She worked at the <u>State Department</u> under the Carter administration and served on the <u>National Security Council</u> as the <u>Soviet and Eastern Europe</u> Affairs Advisor to President <u>George H. W. Bush</u> during the <u>dissolution of the Soviet Union</u> and <u>German reunification</u> from 1989 to 1991. Rice later pursued an academic fellowship at <u>Stanford University</u>, where she later served as <u>provost</u> from 1993 to 1999. On December 17, 2000, she joined the <u>Bush administration</u> as <u>National Security Advisor</u>. In Bush's second term, she became Secretary of State.

Following her confirmation as Secretary of State, Rice pioneered the policy of <u>Transformational Diplomacy</u> directed toward expanding the number of responsible democratic governments in the world and especially in the <u>Greater Middle East</u>. That policy faced challenges as <u>Hamas</u> captured a popular majority in <u>Palestinian</u> elections, and influential countries including Saudi Arabia and Egypt maintained authoritarian systems (with U.S. backing). While in the position, she chaired the <u>Millennium Challenge Corporation</u>'s board of directors. [3]

In March 2009, Rice returned to <u>Stanford University</u> as a political science professor and the Thomas and Barbara Stephenson Senior Fellow on Public Policy at the <u>Hoover Institution</u>. [4][5] In September 2010, she became a faculty member of the <u>Stanford Graduate School of Business</u> and a director of its Global Center for Business and the Economy. [6] In January 2020, it was announced that Rice would succeed <u>Thomas W. Gilligan</u> as the next director of the Hoover Institution on September 1, 2020. [7]

She is on the Board of Directors of Dropbox and Makena Capital Management, LLC

# **COLIN POWELL**

American Politician, Retired Four-Star General \*recommended by Dr. David Dodick

# Bio Link: <a href="https://en.wikipedia.org/wiki/Colin Powell">https://en.wikipedia.org/wiki/Colin Powell</a>

#### 03

Second suggestion for a public board member (non-neurologist):

Name:	Colin Powell
Reason for recommendation:	Enormous influence
Relationship (if any):	I don't but another of our board members may.

#### Q4

Please indicate which of the following characteristics, experiences, skills, expertise, or locations apply to your second public member recommendation:

Excellent communicator

Access/connections to affluent individuals

Access/connections to corporations

Access/connections to foundations

Diversity

Major donor capacity

Located in a city of high-wealth concentration (i.e. New York, San Francisco, LA, Chicago, DC, Houston, Dallas, Atlanta, Seattle, San Diego, or Boston)

Colin Luther Powell is an American politician and retired four-star general in the <u>United States Army</u>. During his military career, Powell also served as <u>National Security Advisor</u> (1987–1989), as Commander of the <u>U.S. Army Forces Command</u> (1989) and as <u>Chairman of the Joint Chiefs of Staff</u> (1989–1993). He played major roles in the invasion of Panama in 1989 and especially the <u>Persian Gulf War</u> against Iraq in 1990–1991. He was the <u>65th United States Secretary of State</u>, serving under Republican President <u>George W. Bush</u>. He was the <u>first African-American to serve as Secretary of State</u>. His term was highly controversial regarding his inaccurate justification for America's <u>Iraq War</u> in 2003. He was fired after Bush was reelected in 2004.

Powell was born in New York City in 1937 and was raised in the South Bronx. His parents, Luther and Maud Powell, immigrated to the United States from Jamaica. Powell was educated in the New York City public schools, graduating from the City College of New York (CCNY), where he earned a bachelor's degree in geology. He also participated in ROTC at CCNY and received a commission as an Army second lieutenant upon graduation in June 1958. Powell was a professional soldier for 35 years, during which time he held many command and staff positions and rose to the rank of 4-star general. His last assignment, from October 1, 1989, to September 30, 1993, was as the 12th Chairman of the Joint Chiefs of Staff, the highest military position in the Department of Defense. During this time, he oversaw 28 crises, including Operation Desert Storm in the 1991 Persian Gulf War. He formulated the Powell Doctrine which limits American military action unless it satisfies criteria regarding American national security interests, overwhelming force, and widespread public support.

In retirement, Powell wrote his autobiography, *My American Journey*. He pursued a career as a public speaker, addressing audiences across the country and abroad. Prior to his appointment as Secretary of State, Powell was the chairman of <a href="America's Promise">America's Promise</a> – The Alliance for Youth, a national nonprofit organization dedicated to mobilizing people from every sector of American life to build the character and competence of young people. Powell is the recipient of numerous U.S. and foreign military awards and decorations. Powell's civilian awards include the <a href="Presidential Medal of Freedom">Presidential Medal of Freedom</a> (twice), the President's <a href="Citizens Medal">Citizens Medal</a>, the <a href="Congressional Gold Medal">Congressional Gold Medal</a>, the Secretary of State Distinguished Service Medal, and the Secretary of Energy Distinguished Service Medal. Several schools and other institutions have been named in his honor and he holds honorary degrees from universities and colleges across the country. <a href="Citation needed">Citation needed</a>

In 2016, while not a candidate for <u>that year's election</u>, Powell <u>received three electoral votes</u> for the office of <u>President of the United States</u>. [6] On June 7, 2020, Powell announced that he will be voting for former Vice President <u>Joe Biden</u> in the <u>2020 presidential</u> election. [7]

# **MIKE HANYES**

Former NFL Professional Football Player \*recommended by Dr. David Dodick

# Bio Link: <a href="https://en.wikipedia.org/wiki/Mike Haynes (cornerback">https://en.wikipedia.org/wiki/Mike Haynes (cornerback)</a>

#### Q5

Third suggestion for a public board member (non-neurologist):

Name:	Mike Haynes
Reason for recommendation:	Replace outgoing board member who is a star athlete. Also, passionate about concussion prevention and is a member of the Concussion Legacy Foundation.
Relationship (if any):	Acquaintance. Spoke for me at a concussion symposium I chaired.
Contact information:	Also, one of our board members almost certainly knows him.
Additional comments:	NFL Pro Football Hall of Fame; Super Bowl Champion

#### 06

Please indicate which of the following characteristics, experiences, skills, expertise, or locations apply to your third public member recommendation:

Highly social
Excellent communicator
Access/connections to affluent individuals
Access/connections to corporations
Access/connections to foundations
Diversity
Major donor capacity

Located in a city of high-wealth concentration (i.e. New York, San Francisco, LA, Chicago, DC, Houston, Dallas, Atlanta, Seattle, San Diego, or Boston)

Michael James Haynes is an American former professional <u>football</u> player who was a <u>cornerback</u> in the <u>National Football</u> <u>League</u> (NFL) for the <u>New England Patriots</u> and the <u>Los Angeles Raiders</u>. He used his speed, quickness and range to become both a premier <u>defensive back</u> and an outstanding <u>punt return specialist</u>. Haynes was inducted into the <u>College</u> Football Hall of Fame in 2000 and the Pro Football Hall of Fame in 1997.

Haynes went to T.S. King Middle School, as stated by him in the 2012 recognition for his Hall of Fame (NFL) awards. Haynes played cornerback at John Marshall High School in Los Angeles. The team on which he played chose two all star players to represent Marshall, which would eventually lead to his further career. In addition to football, Haynes also participated in track and field and currently holds the long jump record at John Marshall. During his Senior Year (1971) Haynes started both ways on offense (QB) and defense (Cornerback). However, Marshall went 0-7-1 in the Northern League in 1971 and tied Belmont 20–20 in his final game. In a show of his athletic accomplishments, John Marshall High School named the school football stadium in his honor when he was inducted into the school football hall of fame in 1986.

In his final regular season track meet, Haynes had to run the final leg of the Mile Relay, then rest before completing his final long jump effort. The opposing team (archrival Belmont), believing they had won the league championship, loaded their bus and went home. Haynes rested, then leaped 23'5", a school record that still stands, winning the event, the meet and the league championship with it.

At Arizona State, Haynes was a three-time All-Western Athletic Conference selection, and a two-time All-America selection. In 2001, he was inducted into the College Football Hall of Fame.

#### MIKE HANYES - PAGE 2

#### Professional football career

**New England Patriots** Haynes was selected in the first round in the 1976 NFL Draft by the New England Patriots. He enjoyed a sensational rookie year with the Patriots with eight interceptions and an AFC-leading 608 yards on 45 punt returns. That year, Haynes gave the Patriots their first-ever touchdowns on punt returns with 89-yard and 62-yard returns. He earned a Pro Bowl invitation as a rookie, the first of nine Pro Bowl bids. He also won NFL Defensive Rookie of the Year honors. The 1976 Patriots had an 11–3 record and clinched a playoff berth for the first time in 13 years. In the first round the Patriots lost to Oakland Raiders 24–21. In the 1978 season Haynes had a total of 6 interceptions, one of which was returned for a touchdown against the Baltimore Colts. The Patriots won the division but lost to the Houston Oilers in the playoffs. Haynes played 4 more seasons with New England with 9 picks and a single touchdown in 1980 against the rival New York Jets.

Haynes recorded 28 interceptions and 1,159 yards on 111 returns, a 10.4-yard average during his seven years with the Patriots. He started his career with 58 consecutive starts before being sidelined with a rib injury late in 1979. Haynes was inducted into the Patriots Hall of Fame in 1994 and number was retired as well.

Los Angeles Raiders Haynes played out his option with the Patriots in 1982, and in November 1983, his contract was awarded to the Los Angeles Raiders in a settlement that gave the Patriots a No. 1 draft choice in 1984 and a No. 2 pick in 1985. After playing the last five regular season games, he started in the Raiders' Super Bowl XVIII victory, notching one interception, two pass breakups and one tackle. His partner in the Raiders' secondary was Lester Hayes, and the tandem was quickly recognized as one of the best cornerback duos in league history.<sup>[1]</sup> Washington Redskins general manager Bobby Beathard later said that Haynes tipped the balance heavily in the Raiders' favor. The Raiders and Redskins had played in the regular season when Haynes was still a Patriot, and his addition gave the Raiders the luxury of having two shutdown corners.<sup>[2][page needed]</sup>

In seven seasons with the Raiders, Haynes returned only one punt but he added 18 interceptions to give him a career total of 46 which were returned for 688 yards and two touchdowns, including a team-record 97-yard return against Miami in 1984. Haynes was an All-Pro choice in 1977, 1978, 1982, 1984 and 1985 and an All-AFC pick eight times.

In 1997, he was elected to the Pro Football Hall of Fame. In 1999, he was ranked number 93 on *The Sporting News'* list of the 100 Greatest Football Players. He is ranked number 49 on the NFL Network Top 100 Greatest Players. [3] Haynes is considered by many football experts to be the best overall cornerback in the history of the NFL.

# **GLENNA STEELE**

Executive Director – Glut1 Deficiency Foundation \*recommended by Darryl De Vino

Bio/Info Links: <a href="https://www.g1dfoundation.org/leadership-team.html">https://globalgenes.org/2020/02/27/rare-leader-glenna-spencer-steele-executive-director-of-glut1-deficiency-foundation/</a>

#### Q1

First suggestion for a public board member (non-neurologist):

Name:	Glenna Steele	
Reason for recommendation:	Very effective Executive Director, well connected in the rare disease space	
Relationship (if any):	none; I work closely with her professionally and respect her as a dedicated person	
Contact information:	gsteele@G1D Foundation.org	
Additional comments:	Outstanding dedicated person supported by the CZI program	

#### Q2

Please indicate which of the following characteristics, experiences, skills, expertise, or locations apply to your first public member recommendation:

Highly social	
Excellent communicator	
Leader/influential within the AAN or public sector	
Access/connections to affluent individuals	
Access/connections to corporations	
Access/connections to foundations	
Diversity	

Connected to the mission/vision of ABF  $\,$ 

Glenna Steele holds a BS and MED in Education from Eastern Kentucky University. She has spent 15 years teaching public school kindergarten and first grade in Florida and Kentucky.

She has been a volunteer with the Epilepsy Foundation of Kentuckiana and Kentucky Special Olympics. Glenna was as a founding board member, first President and first Education Director of the Glut1 Deficiency Foundation.

She lives in Owingsville, Kentucky with her husband, John, and their daughters, Macie and Maggie. Macie was diagnosed with Glut1 Deficiency in 2008 at the age of 10.

# **LEN SCHLEIFER**

Co-founder and Chief Executive Regeneron Pharmaceuticals \*recommended by unknown

Bio/Info Links: <a href="https://en.wikipedia.org/wiki/Leonard">https://en.wikipedia.org/wiki/Leonard</a> Schleifer & <a href="https://www.forbes.com/profile/leonard-schleifer/#66600fec24d8">https://www.cnbc.com/2020/03/03/regeneron-ceo-hopes-to-have-coronavirus-treatment-made-near-august.html</a>

Major donor capacity

Connected to the mission/vision of ABF

First suggestion for a public board member (non-neurologist):

Name: Len Schleifer

Reason for recommendation: CEO Regeneron

Relationship (if any): remote relationship - he is a neurologist

Q2

Please indicate which of the following characteristics, experiences, skills, expertise, or locations apply to your first public member recommendation:

Access/connections to affluent individuals

Access/connections to corporations

Access/connections to foundations

Located in a city of high-wealth concentration (i.e. New York, San Francisco, LA, Chicago, DC, Houston, Dallas, Atlanta, Seattle, San Diego, or Boston)

Leonard S. Schleifer is the co-founder and chief executive of the <u>biotechnology</u> company <u>Regeneron Pharmaceuticals</u>. He was born and raised in a <u>Jewish</u> family, the son of Florence and Charles Baker Schleifer, in <u>Queens, New York</u>. His father was a sweater manufacturer and <u>World War II codebreaker</u>. He graduated with a B.S. from <u>Cornell University</u> and a MD-PhD from the <u>University of Virginia</u> where he studied under future Nobel Laureate, <u>Alfred G. Gilman</u>. He then worked at <u>New York Hospital</u> where he trained to become a <u>neurologist</u> and also served as a junior faculty member.

Noticing that the biotechnology company <u>Genentech</u> was conducting state-of-the-art research but not on diseases of the nervous system, he determined to get into the biotechnology business. After rebuking Gilman's efforts to recruit him as an academic, he found a sponsor in George Sing, a venture capitalist at <u>Merrill Lynch</u>, and obtained \$1 million in seed capital. He also recruited <u>George Yancopoulos</u>, a 28-year-old scientist, to be his partner, and in 1988 they founded Regeneron Pharmaceuticals. After several years of trying to recruit research doctors many of whom preferred to work in academia or for large corporations, they developed their first drug to treat <u>Lou Gehrig's disease</u>. It was a failure as was their second drug to treat <u>obesity</u>. Thereafter, they invited the former <u>Merck & Co.</u> CEO <u>Roy Vagelos</u> to be the chairman of their company and to help to turn the company around. He implemented two strategic changes; only invest in drugs in which the biology of the disorder is fully understood; and do not underestimate the importance of human testing to ensure that what works in the laboratory will also work in the real world.

**Eylea** As CEO of Regeneron, Schleifer oversaw the "approval and growth of high-priced drugs." In 2011, Regeneron's first successful drug was <u>Eylea</u> for <u>age-related macular degeneration</u>. Eylea prevented leaky blood vessels in the eye from causing blindness. He licensed the drug to <u>Aventis</u> which was then bought by <u>Sanofi</u> which had no interest in the eye drug. Sanofi, in order to get out of its commitment, paid Regeneron \$50 million and ceded the rights back to Regeneron. The drug was a blockbuster generating \$838 million in its first full year and sales increased 55% to \$1.3 billion in 2013 making Schleifer a billionaire. In 2014 Eylea grossed \$1.735 billion.

As CEO Schleifer received a total compensation of \$41,965,424 in 2014. According to the "annual collaborative report" from Equilar and The New York Times, Schleifer ranked 15th in the May 2015 list of "200 highest-paid CEOs of large publicly traded companies." He ranked first in the list of biopharmaceutical executives with the highest total compensation.

#### LEN SCHLEIFER - PAGE 2

**COVID-19 drugs** The subject is currently working on a multi-center, double-blind, Phase 2/3 trial with the partnership Sanofi, to evaluate the antibody agent, Kevzara(TM) for hospitalized patients starting in March 2020, as well as, working on the development of a novel, multi-antibody cocktail to be used as both a prevention of <u>SARS-CoV-2</u> and treatment for infected patients.

He is married to Harriet (née Partel) Schleifer; they have two children, Adam and David. Harriet has an undergraduate degree from Cornell University, two graduate degrees in education from the University of Virginia and a J.D. degree from St. John's University School of Law. She also serves as a member of the Board of Governors of American Jewish Committee<sup>[8]</sup> and as president of her synagogue. His son Adam is currently one of many candidates running for the nomination in the Democratic Primary for New York's 17th congressional district.

# **FATEMA "TEMA" BURKEY**

Attorney, Real Estate Advisor \*recommended by Jane Ransom

Bio Link: <a href="https://www.evrealestate.com/bio/FatemaBurkey">https://www.evrealestate.com/bio/FatemaBurkey</a>

Fatema Burkey, Real Estate Advisor joined the Gottesman Chapin Group in November 2019, she is a licensed attorney in Pennsylvania and Washington and is thrilled to apply her professional education and experience in her role as a Real Estate Advisor with Engel & Völkers. Originally from Philadelphia, Tema graduated from Georgetown University with a B.S. in Languages and Linguistics in 1998.

Tema moved to New York City after college and worked for two years as Assistant to the Chief Publishing Officer for Marcel Dekker, a medical publishing firm. Tema then attended Washington University School of Law, focusing on international law and human rights, and served on the Editorial Board for The Washington University Law Quarterly. After graduating from law school in 2003, Tema returned to the Philadelphia area, and joined Chimicles & Tikellis, a complex litigation firm.

In 2015, Tema relocated with her family to Seattle and joined Mercer Island Law Group, a boutique employment law firm, before joining Engel & Völkers. Tema is President of The Mary E. Groff Charitable Trust, a private foundation funding medical science, research, and education.

Tema volunteers with several local nonprofit boards, including The Mercer Island Schools Foundation, The Mercer Island Chamber of Commerce, and TheFilmSchool of Seattle. She serves on the Alumni Admissions Committee for Georgetown University's Seattle chapter and the Seattle Regional Cabinet for Washington University in Saint Louis.

Tema speaks French fluently and is a Shakespeare nerd. She enjoys live music, travel, pilates, yoga, tennis, hiking, Persian cuisine, and a Perfect Manhattan.

# **NEAL KASSELL, MD**

Founder & Chairman of Focused Ultrasound Foundation & Former Co-Chair of Neurosurgery at University of Virginia
\*recommended by Richard Satava, MD

Bio/Info Links: <a href="https://www.fusfoundation.org/the-foundation/leadership/the-team/neal-kassell">https://www.fusfoundation.org/the-foundation/leadership/the-team/neal-kassell</a> & https://www.michaeljfox.org/researcher/neal-kassell-md

Dr. Neal Kassell is the founder and chairman of the Focused Ultrasound Foundation and former Co-Chair of Neurosurgery at the University of Virginia.

He has published more than 500 scientific papers and book chapters, and his research has been supported by over \$30 million in NIH and industry grants and contracts. A member of numerous medical societies in the United States and abroad, he has served on many standing and ad hoc committees of the National Institutes of Health and in an editorial capacity for a variety of academic journals. In April 2016, he was named to the Blue Ribbon Panel of Vice President Joe Biden's Cancer Moonshot Initiative.

Dr. Kassell is a founder of numerous private ventures including Interax, Inc.; the Virginia Neurological Institute; Multimedia Medical Systems, Inc.; the Neuroclinical Trials Center; the NeuroVenture Fund; and MedSpecialists.net. He has served on a number of corporate and not-for-profit boards, including Eclypsis Corporation; INC Research; the Prostate Cancer Foundation; Insightec, Ltd.; the Expedition Trust Company; Tuesday Evening Concert Series and Virginia National Bank, and is currently a director of the Focused Ultrasound Foundation.

He is a shareholder in Insightec, Ltd., where he also served on the board until 2012.

Dr. Kassell received his undergraduate and medical education at the University of Pennsylvania.

# **JOANNE BERGER-SWEENEY**

Neuroscientist & 22<sup>nd</sup> President of Trinity College \*recommended by Jane Ransom

Bio/Info Links: <a href="https://en.wikipedia.org/wiki/Joanne">https://en.wikipedia.org/wiki/Joanne</a> Berger-Sweeney & <a href="https://www.trincoll.edu/president/about-president-berger-sweeney/">https://www.trincoll.edu/president/about-president-berger-sweeney/</a>

Joanne E. Berger-Sweeney is an American <u>neuroscientist</u> and the 22nd president of <u>Trinity College</u>, Hartford, Connecticut. She is the first African-American and the first woman to serve in the position. Earlier in her career, Berger-Sweeney did proof-of-concept work on galantamine (brand name Razadyne), the second-most used drug to treat Alzheimer's disease.

Berger-Sweeney was born in <u>Los Angeles</u>. Her parents met at <u>Clark College</u>. Her father earned his law degree at <u>Howard University</u>, finishing second in his class. [2] Her mother was Executive Director of the Los Angeles Girl Scouts Council and was the first African-American woman to lead a Girl Scouts Council in a major metropolitan area.

Berger-Sweeney attended Holman United Methodist Church in Los Angeles. Later in life, at her first commencement ceremony at Trinity College, Berger-Sweeney asked civil rights leader and former Holman UMC pastor Rev. James Morris Lawson, Jr. to speak.

Berger-Sweeney attended Wellesley College, where she earned an undergraduate degree in psychobiology (neuroscience) in 1979. She received a Masters of Public Health from the University of California, Berkeley in 1981. Berger-Sweeney completed her doctoral work in neurotoxicology with Joseph T. Coyle at Johns Hopkins Bloomberg School of Public Health in 1989. Berger-Sweeney did proof-of-concept work on galantamine (brand name Razadyne), showing that the drug reversed memory deficits in mice. Her work served as the foundation for clinical trials by Janssen Pharmaceutica, culminating in the drug's approval by the FDA. [9] Galantamine is the second-most-used Alzheimer's drug in the world.

Berger-Sweeney received her PhD in 1989. She completed her postdoctoral training at the National Institute of Health (<u>Inserm</u>) in Paris, France.

Career - Berger-Sweeney returned to Wellesley in 1991 to teach and conduct research. [1] She was the first African-American woman at Wellesley to become a full professor and was named the Allene Lummis Russell Professor in Neuroscience. During her tenure at Wellesley, she served as Director of the neuroscience program and as Associate Dean of the College.

In 2010, Berger-Sweeney became Dean of the School of Arts and Sciences at <u>Tufts University</u>, where she served until 2014, during which time she strengthened the school's faculty and interdisciplinary programs. She helped create the Center for Race and Democracy at Tufts, which studies the impact of race on individuals' lives. She also led the creation of the Bridge to Liberal Arts Success at Tufts (BLAST) program that supports college students from underserved high schools.

On October 26, 2014, she became the first woman and the first African American to lead <u>Trinity College (Connecticut)</u>. In 2018, the college renewed her contract through 2024. Berger-Sweeney has overseen several important initiatives at Trinity, including a new strategic plan that will guide the college through 2023; a new mentoring program for incoming students (the Bantam Network); a new campus initiative to promote respect and inclusion; and an expansion into downtown Hartford. During her tenure at Trinity College, Berger-Sweeney was involved in several controversies that garnered national media attention.

Berger-Sweeney serves as a Director at <u>Hartford Hospital</u>, Inc and Hartford HealthCare Corporation. She chairs the professional development committee of the <u>Society for Neuroscience</u>, is on the board of directors for the <u>AFS Intercultural Programs/USA</u>, and is a Trustee and chair of the Academic Affairs Committee for <u>Framingham State University</u>. She is also a member of the board of trustees of Cold Spring Harbor Laboratory.

Berger-Sweeney has received grants from the <u>National Institutes of Health</u> and the <u>National Science Foundation</u>, as well as from private foundations, for her work on the neurobiology of <u>learning</u> and <u>memory</u>, with applications to <u>neurodevelopmental disorders</u>. She has authored or co-authored more than 60 scientific articles.

Berger-Sweeney has received a number of awards for her scientific work, including the following:

- Member, <u>Sigma Xi</u> (1992)
- Young Investigator Award, National Science Foundation (1994)
- Member, The Dana Alliance for Brain Initiatives
- Lifetime Mentoring Award, Society for Neuroscience (2006)
- Fellow, American Association for the Advancement of Science (2012)
- Distinguished Alumna Award, Johns Hopkins School of Public Health (2015)
- Member, American Academy of Arts and Sciences (2018)

Berger-Sweeney's husband, Urs V. Berger, is a neuroscientist and computer scientist. They have two children.

# **SANJAY GUPTA**

Neurosurgeon, Medical Reporter & Writer

Houston, Dallas, Atlanta, Seattle, San Diego, or Boston)

Associate Chief of Neurosurgery Service at Grady Memorial Hospital, Atlanta & Associate Professor or Neurosurgery at the Emory University School of Medicine & Chief Medical Correspondent for CNN \*recommended by Dr. David Dodick

Bio/Info Links: <a href="https://en.wikipedia.org/wiki/Sanjay">https://en.wikipedia.org/wiki/Sanjay</a> Gupta & <a href="https://en.wiki/Sanjay">https://en.wiki/Sanjay</a> Gupta & <a href="https://en.wiki/Sanjay</a> Gupta & <a href="https

#### **Q7**

First suggestion for a neurologist board member: *Cannot be a member of the AAN Board		
Name:	Sanjay Gupta	
Reason for recommendation:	Neurosurgeon with enormous reach and influence who would raise the visibility and stature of our board	
Relationship (if any):	None	
Q8		
Please indicate which of the follo member recommendation:	wing characteristics, experiences, skills, expertise, or locations apply to your first neurologist	
Highly social		
Excellent communicator		
Access/connections to affluent individ	uals	
Access/connections to corporations		
Access/connections to foundations		
Major donor capacity		
Connected to the mission/vision of AB	F	
Located in a city of high-wealth conce	ntration (i.e. New York, San Francisco, LA, Chicago, DC,	

**Sanjay Gupta** is an American <u>neurosurgeon</u>, <u>medical reporter</u>, and writer. He serves as associate chief of the neurosurgery service at <u>Grady Memorial Hospital</u> in <u>Atlanta, Georgia</u>, and as associate professor of <u>neurosurgery</u> at the <u>Emory University School of Medicine</u> and Chief Medical Correspondent for <u>CNN</u>.

Gupta is known for his many TV appearances on health-related issues. First and foremost, he is the Chief Medical Correspondent for <u>CNN</u>. During the <u>2020 coronavirus pandemic</u>, he has been a frequent contributor to numerous <u>CNN</u> shows covering the crisis, as well as hosting a weekly Town Hall with <u>Anderson Cooper</u>. Gupta is the host of the <u>CNN</u> show <u>Sanjay Gupta MD</u> for which he has won multiple <u>Emmy Awards</u>. Gupta also hosted the 6 part mini series, Chasing Life. He is a frequent contributor to other CNN programs such as <u>American Morning</u>, <u>Larry King Live</u>, <u>CNN Tonight</u>, and <u>Anderson Cooper 360</u>°. His reports from <u>Charity Hospital</u>, <u>New Orleans</u>, Louisiana, in the wake of <u>Hurricane Katrina</u> led to him winning a 2006 Emmy Award for <u>Outstanding Feature Story in a Regularly Scheduled Newscast</u>. He is also a special correspondent for CBS News.

Dr. Sanjay Gupta also Co-Hosts the health conference, Life Itself, along with <u>Marc Hodosh</u> (Co-Creator, TEDMED). Gupta published a column in <u>Time</u> magazine and has written four books: *Chasing Life*, *Cheating Death*, *Monday Mornings: A Novel*, and *Keep Sharp* (Jan 2021).

#### SANJAY GUPTA - PAGE 2

In the 1960s, Gupta's parents, Subhash and Damyanti Gupta, moved from India prior to their marriage and met in Livonia, Michigan, where they worked as engineers for Ford Motor Company. Gupta and his younger brother Suneel graduated from Novi High School and Gupta went on to receive his Bachelor of Science degree in biomedical sciences at the University of Michigan in Ann Arbor, and his M.D. degree from the University of Michigan Medical School in 1993. He was part of Inteflex, a since discontinued accelerated medical education program that accepted medical students directly from high school.

As an undergraduate, Gupta worked as an orientation leader for the freshman orientation program and was a member of the Men's Glee Club. He also served as president of the Indian American Students Association (IASA), which is now the second-largest student organization at the university.

Gupta completed his residency in neurological surgery within the <u>University of Michigan Health System</u>, in 2000, followed by a fellowship at the Semmes Murphy Clinic, in Memphis, Tennessee. Gupta plays the accordion, having taken ten years of lessons, as he noted in an interview with David Hochman for *Playboy*.

Career - Gupta is an Emory Healthcare general neurosurgeon at Grady Memorial Hospital and has worked on spine, trauma and 3-D-image-guided operations. He has published medical journal articles on percutaneous pedicle screw placement, prain tumors, and spinal cord abnormalities. As of May 2020 he is not licensed to practice medicine in New York. His license to practice and prescribe controlled substances in Michigan expired January 2014. His license to practice in South Carolina expired March 2002. He is licensed to practice medicine in Georgia.

During his reporting in Haiti following the <u>January 2010 earthquake</u>, Gupta received a call from the <u>aircraft carrier USS Carl Vinson</u> that an earthquake victim, a 12-year-old girl, was aboard and needed a neurosurgeon. Gupta, a <u>pediatric surgeon</u>, <u>Henri Ford</u>, and two <u>U.S. Navy</u> doctors removed a piece of concrete from the girl's skull in an operation performed aboard the *Vinson*. Ford later wrote that Gupta "proved to be a competent neurosurgeon".

From 1997 to 1998, he served as one of fifteen <u>White House Fellows</u>, primarily as an advisor to <u>Hillary Clinton</u>. In January 2009, it was reported that Gupta was offered the position of <u>Surgeon General of the United States</u> in the <u>Obama administration</u>, but he withdrew his name from consideration.<sup>[24]</sup>

Broadcast journalism, television, film & events - In 2003, Gupta traveled to Iraq to cover the medical aspects of the <u>invasion of Iraq</u>. While in Iraq, Gupta performed emergency surgery on both US soldiers and Iraqi civilians.¹ Gupta was embedded with a <u>Navy</u> medical unit at the time, specifically a group of <u>Corpsman</u> called the "Devil Docs", who supported the <u>1st Marine Expeditionary Force</u>. A <u>Marine</u> named Jesus Vidana suffered a severe head injury, and the Marines asked for Gupta's assistance because of his background in neurosurgery. Vidana survived and was sent back to the United States for rehabilitation. In December 2006, CBS News president <u>Sean McManus</u> negotiated a deal with CNN that would have Gupta file up to ten reports a year for the <u>CBS Evening News with Katie Couric</u> and <u>60 Minutes</u> while remaining CNN's chief medical correspondent and associate chief of neurosurgery at Grady Memorial Hospital.

On October 14, 2007, Gupta guest-hosted a health episode of <u>CBS News Sunday Morning</u> as its regular host <u>Charles Osgood</u> was on vacation. In February 2009, Gupta hosted <u>AC360</u> covering the White House Health Summit. He also guest hosted <u>Larry King Live</u> in October 2009. In January 2010, Gupta and Cooper led CNN's coverage of the earthquake in <u>Haiti</u>. Gupta has regularly appeared on the <u>Late Show with David Letterman, The Late Show with Craig Ferguson</u>, <u>The Daily Show with Jon Stewart</u>, <u>Real Time with Bill Maher</u> and <u>the Oprah Winfrey Show</u>. Winfrey referred to Gupta as CNN's hero in January 2010.

In 2011, Gupta portrayed himself in the movie <u>Contagion</u>, which has received much renewed attention during the 2020 coronavirus pandemic. [32]

His novel *Monday Mornings* became an instant *New York Times* bestseller on its release in March 2012. It was adapted as a 2013 television series with David E. Kelley and Gupta serving as executive producers.

In a 2013 editorial, Gupta announced that in the process of working on a documentary about <u>marijuana</u> he had changed his mind about the drug's <u>risks and benefits</u>. Gupta had previously criticized laws that allowed patient access to <u>medical marijuana</u>, but he reversed his stance, saying, "I am here to apologize," and, "We have been terribly and systematically misled for nearly 70 years in the United States, and I apologize for my own role in that."

[33] The third part of his 3-hour documentary, "Weed 3: The Marijuana Revolution", was released in April 2015.

Gupta served as a commentator on the <u>University of Michigan</u> TeamCast with former Wolverines kicker <u>Jay</u> <u>Feely</u> for the school's appearance in the <u>2018 NCAA Men's Final Four</u>, which aired on CNN sibling <u>TNT</u>. [35]

#### SANJAY GUPTA - PAGE 3

In April 2019, *Chasing Life* was adapted as a six-show TV miniseries on <u>CNN</u> that took him to Japan, India, Bolivia, Norway, Italy, and Turkey.<sup>[36]</sup>

In September 2019, Gupta and Marc Hodosh (Co-Creator of TEDMED) announced a new event called Life Itself in partnership with CNN. Both Gupta and Hodosh will serve as hosts and organizers.

Surgeon General Candidate - On January 6, 2009, CNN announced that Gupta had been considered for the position of <u>Surgeon General</u> by President <u>Barack Obama</u>. Some doctors said that his communication skills and high-profile would allow him to highlight medical issues and prioritize medical reform. Others raised concerns about potential <u>conflicts of interest</u> with drug companies who have sponsored his broadcasts and his lack of skepticism in weighing the costs and benefits of medical treatments. In March 2009 Gupta withdrew his name from consideration for the post, citing his family and his career.

Honors - On April 28, 2012, Gupta was awarded an honorary Doctor of Humane Letters degree for his accomplishments in the medical field. He also gave the commencement address at the spring commencement ceremony held in the <u>University of Michigan</u> Stadium. On June 12, 2016, Gupta addressed the <u>Oregon Health & Science University</u> graduating class of 2016. On May 23, 2019, Dr. Gupta presented the commencement address to the Albert Einstein College of Medicine class of 2019.

In October 2019, Dr. Gupta was elected to the National Academy of Medicine, to join its 2019 class consisting of 100 members, one of the highest honors in medicine.

In 2003, Gupta was also named one of the sexiest men of the year by *People* magazine.

Gupta is married to Rebecca Olson, a <u>family law</u> attorney. They were married in 2004 in a <u>Hindu</u> wedding ceremony. They live in Atlanta and have three daughters.

### **MAYIM BIALIK**

American Actress, Neuroscientist, and Author \*recommended by Dr. David Dodick

Bio/Info Links: <a href="https://en.wikipedia.org/wiki/Mayim Bialik">https://en.wikipedia.org/wiki/Mayim Bialik</a> &

https://www.youtube.com/channel/UCTOocPnDh2YQZZwh86K2OxA &

https://www.imdb.com/name/nm0080524/ & https://www.pbs.org/wgbh/nova/article/the-secret-life-of-scientists-and-engineers-mayim-bialik/

#### Q11

Third suggestion for a neurologist board member: \*Cannot be a member of the AAN Board

Name:	Mayim Bialik
Reason for recommendation:	Neuroscientist and influential celebrity
Relationship (if any):	None
Additional comments:	Featured in Brain and Life in 2018

#### Q12

Please indicate which of the following characteristics, experiences, skills, expertise, or locations apply to your third neurologist member recommendation:

Highly social		
Excellent communicator		
Access/connections to affluent individuals		
Access/connections to corporations		
Gender Diversity		
Major donor capacity		

**Mayim Chaya Bialik** is an American actress, neuroscientist, and author. From 1991 to 1995, she played the title character of the <u>NBC</u> sitcom <u>Blossom</u>. She later played neurobiologist <u>Amy Farrah Fowler</u> on the <u>CBS</u> sitcom <u>The Big Bang Theory</u> from 2010 to 2019. Outside of her acting career, she holds a <u>Ph.D.</u> in neuroscience. For her role as Fowler, Bialik has been nominated four times for the <u>Primetime Emmy Award for Outstanding Supporting Actress in a Comedy Series</u> and won the <u>Critics' Choice Television Award for Best Supporting Actress in a Comedy Series in 2015 and 2016.</u>

Mayim Chaya Bialik was born in <u>San Diego</u>, <u>California</u>, to Barry and Beverly (née Winkleman) Bialik. Her family were Jewish immigrants who lived in <u>The Bronx</u>, New York City, and three of her four grandparents migrated from Poland, Czechoslovakia, and Hungary. She was raised as a <u>Reform Jew</u>, but now considers herself to be <u>Modern Orthodox Jewish</u>. She had a <u>Bat Mitzvah</u>. She has also described herself as a "staunch <u>Zionist</u>". Her personal name, Mayim ('water' in <u>Hebrew</u>), originates in a mispronunciation of <u>Miriam</u>, her great-grandmother's name. Poet <u>Hayim</u> Nahman Bialik was her great-grandfather's uncle.

Bialik graduated in 1993 from North Hollywood High School in North Hollywood, California. In acknowledgment of her acting commitments, she was granted a deferred acceptance and attended University of California, Los Angeles (UCLA). She said she wanted to stay close to her parents and did not want to move to the East Coast. She earned a B.S. degree in neuroscience, with minors in Hebrew and Jewish studies, from UCLA in 2000.

#### MAYIM BIALIK – PAGE 2

Bialik stated that she did not have the grades needed for medical school. She went on to study for a doctorate in neuroscience. She took a break from studies in 2005 to return to acting. She returned to earn her <u>Ph.D.</u> degree in neuroscience from UCLA in 2007. Her dissertation was an investigation of <u>hypothalamic</u> activity in patients with <u>Prader–Willi syndrome</u>, entitled "Hypothalamic regulation in relation to <u>maladaptive</u>, <u>obsessive-compulsive</u>, affiliative and satiety behaviors in Prader–Willi syndrome.

Acting career - Bialik started her career as a <u>child actress</u> in the late 1980s. She joined the cast of <u>The Big Bang Theory</u> as <u>Dr. Amy Farrah Fowler</u> in September 2010. Her first appearance was in the season 3 finale as a potential love interest for the character of <u>Sheldon Cooper (Jim Parsons)</u>. In <u>season 4</u>, she began as a recurring character playing Sheldon's "friend that's a girl, but not a girlfriend." Beginning with the 8th episode of season 4, she became part of the main cast. The character Amy is a neurobiologist, which is related to Bialik's real-life doctorate in neuroscience. Bialik's performance in *The Big Bang Theory* earned her <u>Emmy Award</u> nominations in 2012, 2013, 2014, and 2015 for Outstanding Supporting Actress in a Comedy Series. See Link above for complete acting career history.

On August 20, 2019, it was announced that she and her new production company, Sad Clown Productions, had signed exclusive contracts with Warner Bros. Entertainment. Mackenzie Gabriel-Vaught, a former executive at Chuck Lorre Productions, will be head of development for Sad Clown. Sad Clown Productions, in conjunction with Jim Parsons' That's Wonderful Productions, BBC Studios, and Miranda Hart, will be executive producing a starring vehicle for Bialik. Call Me Kat, based on Miranda Hart's BBC series Miranda, will star Bialik in the title role. The series, a co-production of Warner Bros. and Fox Entertainment, will air on Fox starting in Fall 2020.

**Grok Nation** - Bialik founded Grok Nation in August 2015 for people of different ages and backgrounds to have conversations on contemporary issues. It aims to engage readers in online conversations that lead to offline action, mobilizing individuals toward changing the world as a community. To grok means to understand in a profound manner. The term comes from the 1961 science fiction novel <u>Stranger in a Strange Land</u> by <u>Robert A. Heinlein</u>. Bialik had been writing on a similar area for JTA-affiliated Jewish parenting site Kveller for five years. She announced and described her new creation on the site. Along with former Sassy editor Christina Kelly, she relaunched Grok Nation as a women's lifestyle site in March 2018.

**Books** - Bialik has written two books with pediatrician Jay Gordon and two by herself. *Beyond the Sling* is about <u>attachment parenting</u>, while *Mayim's Vegan Table* contains over one hundred vegan recipes written by Bialik. Her third book, called *Girling Up*, is about the struggles and ways in which girls grow up while showing the scientific ways in which their bodies change. The successor to *Girling Up*, *Boying Up*, was released on May 8, 2018. The book analyzes the science, anatomy and mentality of growing up as a male as well as discussing the physical and mental changes and challenges boys face with while transitioning from adolescence to adulthood.

**Film** - Bialik wrote and directed her first film, *As Sick As They Made Us*, about a divorced mom juggling her family's needs and her own quest for love. The movie stars <u>Dustin Hoffman</u> and <u>Candice Bergen</u>. <u>Simon Helberg</u>, Bialik's former <u>The Big Bang Theory</u> castmate, also appears in the film. The film is expected to premier toward the end of 2020.

**Personal life** - Bialik married Michael Stone on August 31, 2003, Bialik and Stone have two sons, Miles (b. 2005) and Frederick (b. 2008). The couple divorced in November 2012.

In 2010, Bialik returned to television so she could spend more time with her children; "I'm glad that I completed my PhD and I'm very proud of it, but the life of a research professor would not have suited my needs in terms of what kind of parenting I wanted to do.

In 2014, Bialik was awarded an honorary Doctor of Humane Letters degree from Boston University.

Bialik is a <u>vegan</u> and a founding member of the Shamayim V'Aretz Institute, a Jewish organization that advocates for the ethical treatment of animals. In 2017, she announced that she and vegan chef Ali Cruddas co-own Bodhi Bowl, a vegan restaurant in <u>Los Angeles</u>. She said on <u>The Late Late Show with James Corden</u> that she identified herself as a <u>feminist</u>.

# CHRISTY JAGDFELD

Treasurer of Dysautonomia International Consultant with PANDAS Network

\*Self-Nominated via email to ABF on 7/16/2020 (see below, she has not been contacted yet)

Bio/Info Links: <a href="http://www.dysautonomiainternational.org/page.php?ID=18">http://www.dysautonomiainternational.org/page.php?ID=18</a>

Email: cjagdfeld@wi.rr.com

Christy Jagdfeld, CPA – Treasurer - Christy holds a B.B.A. in Accounting from the University of Wisconsin-Whitewater. She is a Certified Public Accountant who put accounting on hold to stay home with her three children, where she decided she liked volunteering more than accounting. Christy has volunteered extensively with her local schools by supporting the PTO, and assisting with website development, sports teams and fundraising. She also serves on the board of the local swim team, which two of her kids swim for. Christy's youngest was diagnosed with postural orthostatic tachycardia syndrome and Ehlers-Danlos syndrome in 2014 as a 7th grader. Since then, Christy has been actively researching and raising awareness about dysautonomia as one of the leaders of Dysautonomia International's Wisconsin Support Group. She resides in Mukwonago, Wisconsin with husband Aaron and kids.

Email to ABF Info Box from Christy: I am currently the treasurer of Dysautonomia International and I do some consulting with PANDAS Network. I have a daughter that suffers from several neurological conditions such as POTS (postural orthostatic tachycardia syndrome), EDS (Ehlers Danlos Syndrome), and PANDAS (pediatric autoimmune neuropsychiatric disorders syndrome) - which now has ground breaking research that shows how antibodies break the blood brain barrier. My passion is to advance research into these neurological conditions as well as any research that advances our knowledge of the brain. I would love to find out more about becoming a board member or other areas of need.

## CHRISTIANNE HECK

Professor of Clinical Neurology Co-Director, USC Center for Neurorestoration Medical Director, USC Comprehensive Epilepsy Center \*recommended by Joe Sirven

Bio Link: https://providers.keckmedicine.org/provider/Christianne+N.+Heck/204983

Q7		
First suggestion for a neurologist board member: *Cannot	t be a member of the AAN Board	
Name:	Christianne Heck, MD	
Reason for recommendation:	Well connected; also of means has her own vineyard	
Relationship (if any):	friend	
Additional comments:	Based at USC	
Q8	Leader/influential within the AAN or public sector,	
Please indicate which of the following characteristics,	Access/connections to affluent individuals ,	
experiences, skills, expertise, or locations apply to your first neurologist member recommendation:	Diversity,	
met near oregist member resorming nation.	Major donor capacity,	
	Located in a city of high-wealth concentration (i.e. New York, San Francisco, LA, Chicago, DC, Houston, Dallas, Atlanta, Seattle, San Diego, or Boston)	

Dr. Christianne Heck serves as the Medical Director of the USC Comprehensive Epilepsy Program at the Keck Medical Center in Los Angeles. She served as Chief of Staff at Keck Hospitals of USC from 2015-2017, and serves as Co-Director for the USC Neurorestoration Center.

She is board certified in both neurology and epilepsy. She is a member of the professional advisory board of the Epilepsy Foundation and has served on the Board of Directors of the National Association of Epilepsy Centers (NAECs). From 2011-12, she served on the Institute of Medicine's Committee on the Public Health Dimensions of the Epilepsies assisting in the writing of Epilepsy Across the Spectrum: Promoting Health and Understanding. She has been a member of the Association of California Neurologists Board of Directors, where she actively participated in opinions and discussions regarding patient care and access to care within the state of California.

She volunteers regularly for Hollywood Health and Society of the USC Annenberg School of Communications Norman Lear Center whose goals are the promotion and evaluation of public health topics in film and television.

Her research focuses on innovative approaches to treating epilepsy, including responsive neurostimulation and paradigms for optimizing neuromodulatory therapies, vagus nerve stimulation, epilepsy surgery and Gamma Knife radiosurgery.

Her expertise also includes services to minority populations as well as furthering understanding of status epilepticus, neuronal injury, memory dysfunction, brain machine interfaces and the psychosocial impact of epilepsy. She is keenly interested in quality and access to care for epilepsy patients and families across the nation.

# **MATTHEW STERN**

Director Emeritus of the Parkinson's Disease and Movement Disorders Center, Department of Neurology, University of Pennsylvania Health System, Pennsylvania Hospital \*recommended by Joe Sirven

Bio/Info Links: <a href="https://reachmd.com/profiles/matthew-b-stern-md/jRl8eL/biography/">https://reachmd.com/profiles/matthew-b-stern-md/jRl8eL/biography/</a> & <a href="https://www.pennmedicine.org/news/news-releases/2013/august/penn-medicines-matthew-stern-m">https://www.pennmedicine.org/news/news/news-releases/2013/august/penn-medicines-matthew-stern-m</a>

Q9	
Second suggestion for a neurologist board member: *Car	nnot be a member of the AAN Board
Name:	Matthew Stern, MD
Reason for recommendation:	Connected to many folks of means and is of means himself
Additional comments:	At Penn and amovement disorder MD
Q10	Highly social ,
Please indicate which of the following characteristics,	Excellent communicator,
experiences, skills, expertise, or locations apply to your second neurologist member recommendation:	Access/connections to affluent individuals ,
	Access/connections to corporations,
	Access/connections to foundations,
	Major donor capacity

Matthew Stern, M.D., is the Parker Family Professor Emeritus of Neurology at the Perelman School of Medicine at the University of Pennsylvania and Director Emeritus of the Parkinson's Disease and Movement Disorders Center. Dr. Stern has authored and co-authored numerous papers on Parkinson's and related disorders and edited or coedited eight books. He has served on the executive committee of the American Academy of Neurology's Movement Disorders Section and is a fellow of the American Neurological Association and American Academy of Neurology.

In addition to serving as an institutional investigator for numerous clinical trials, Dr. Stern has been the principal investigator or co-principal investigator of many studies related to Parkinson's and movement disorders. Dr. Stern serves on numerous consulting boards and has lectured throughout the world. He is an inaugural member of Penn's Academy of Master Clinicians and is a past president of the International Parkinson and Movement Disorder Society, which has awarded him its President Distinguished Service Award and an honorary membership

# DIMITRI KRAINC, MD, PhD

Aaron Montgomery Ward Professor of Neurology, chairman of the Department of Neurology and director of the Center for Rare Neurological Diseases (CRND) at Northwestern University Feinberg School of Medicine.
\*recommended by Frances Jensen

Bio Links: <a href="https://www.feinberg.northwestern.edu/faculty-profiles/az/profile.html?xid=28300">https://www.feinberg.northwestern.edu/faculty-profiles/az/profile.html?xid=28300</a> & https://www.michaeljfox.org/researcher/dimitri-krainc-md-phd

Dr. Dimitri Krainc is the Aaron Montgomery Ward Professor of Neurology, chairman of the Department of Neurology and director of the Center for Rare Neurological Diseases (CRND) at Northwestern University Feinberg School of Medicine.

Prior to joining Northwestern, Dr. Krainc spent 20 years at Harvard serving on the neurology faculty at the Massachusetts General Hospital and Harvard Medical School, where he also completed a neurology residency and a fellowship in movement disorders. Using induced pluripotent stem cells ("man-made" stem cells that can become other cell types) from specific neurons from individuals with Parkinson's, Dr. Krainc studies the molecular underpinnings of Parkinson's disease, focusing on genetic forms of disease.

His recent work identified novel lysosomal mechanisms (sites that store enzymes to break down items in the cell) and targets, such glucocerebrosidase (an enzyme made by the GBA gene), to develop targeted therapies for Parkinson's and related synucleinopathies.

## NAVAZ KARANJIA, MD

Medical Director, Neurointensive Care Unit Associate Professor of Neurosciences and Anesthesiology \*recommended by HE Hinson

Bio Link: <a href="https://providers.ucsd.edu/details/12187/navaz-karanjia-neurology-stroke">https://providers.ucsd.edu/details/12187/navaz-karanjia-neurology-stroke</a> care-san diego?utm source=googlemybusiness&utm medium=listings

#### Q7

First suggestion for a neurologist board member: \*Cannot be a member of the AAN Board

Name:	Dr. Navaz Karanjia MD
Reason for recommendation:	Passion for policy and reform at a national level.
Relationship (if any):	colleague/friend
Contact information:	Karanjia, Navaz
Additional comments:	Neurointensivist with excellent personal communication, media skills

#### 08

Please indicate which of the following characteristics, experiences, skills, expertise, or locations apply to your first neurologist member recommendation:

Highly social	
Excellent communicator	
Diversity	

Located in a city of high-wealth concentration (i.e. New York, San Francisco, LA, Chicago, DC, Houston, Dallas, Atlanta, Seattle, San Diego, or Boston)

Navaz Karanjia, MD, is a board-certified neurologist who specializes in caring for people with life-threatening diseases of brain, spinal cord and nerves. She is medical director of UC San Diego Health's Neurocritical Care Program and Neuro-Intensive Care Unit (ICU), which she also founded. The Neuro-ICU team provides around-the-clock expert care, seven days a week, to critically ill patients who may have severe brain injury, stroke or brain tumors, or may be recovering from a neurosurgical procedure.

Dr. Karanjia is an associate professor in the Departments of Neurosciences and Anesthesiology at UC San Diego School of Medicine. Her research interests include early detection of neurologic deterioration and evaluating methods for monitoring cerebral blood flow and intracranial pressure. She has published several book chapters and articles in leading journals, including *Neurocritical Care* and *Archives of Neurology*.

She completed a fellowship in neurocritical care at the Johns Hopkins School of Medicine and a residency in neurology at UCLA School of Medicine. Dr. Karanjia earned her medical degree from Stanford University School of Medicine. She is board-certified in neurology and holds certification in neurocritical care from the United Council for Neurologic Subspecialties.

Dr. Karanjia is a member of many professional organizations, including the American Heart Association/American Stroke Association, the Society of Critical Care Medicine, the Neurocritical Care Society, and the American Academy of Neurology.

# ROBERT GROSS, MD, PhD, FANA, FAAN

Professor, University of Rochester Medical Center - Department of Neurology, Epilepsy & Department of Pharmacology and Physiology
Past Editor-in-chief of Neurology®
\*recommended by Ralph Jozefowicz

Bio Link: <a href="https://www.urmc.rochester.edu/people/22025487-robert-alan-gross">https://www.urmc.rochester.edu/people/22025487-robert-alan-gross</a> & <a href="https://www.aan.com/AAN-Resources/Details/about-the-aan/board-of-directors/robert-a.-gross-md-phd-faan/">https://www.aan.com/AAN-Resources/Details/about-the-aan/board-of-directors/robert-a.-gross-md-phd-faan/</a>

#### Q7

Connected to the mission/vision of ABF

First suggestion for a neurologist board member: *Cannot be a member of the AAN Board			
Name:	Robert Gross, MD		
Reason for recommendation:	Just completed his term as editor of Neurology		
Relationship (if any):	Colleague		
Contact information:	Robert_Gross@urmc.rochester.edu		
Additional comments:	He just rotated off the AAN board as an ex officio member.		
Q8			
Please indicate which of the following c member recommendation:	haracteristics, experiences, skills, expertise, or locations apply to your first neurologist		
Highly social			
Excellent communicator			
Leader/influential within the AAN or public se	ector		

Robert A. Gross MD, PhD, FANA, FAAN graduated from Harvard College with an AB in Biology, summa cum laude, in 1975. He entered the Medical Scientist Training Program at Washington University, St. Louis, earning the MD and PhD (Pharmacology) degrees (1981). He interned in Medicine at the Jewish Hospital in St. Louis and completed residency in Neurology at the Massachusetts General Hospital, where he served as Chief Resident. Faculty positions followed at the University of Michigan (1985-1991) and the University of Minnesota (1991-1994). Dr. Gross joined the faculty of the University of Rochester Medical Center (URMC) in 1994, where he is Associate Chair for Academic Affairs (Neurology). He sees patients in the Strong Epilepsy Center, with a particular interest in the pharmacology of anti-seizure drugs.

Research interests have centered on various aspects of cellular neuropharmacology (regulation of voltage-gated Ca channels by neurotransmitters and therapeutic compounds, regulation of hippocampal neurogenesis by seizures and chemotherapeutic drugs). Collaborative efforts have focused on mechanisms of excitotoxicity. He was involved in several clinical trials of novel anticonvulsants and served on a multi-center task force to design trials to compare brand to generic AEDs. He was the recipient of the S. Weir Mitchell Award of the American Academy of Neurology (AAN) in 1988.

Dr. Gross' educational efforts are diverse. A former director of the interdepartmental Graduate Program in Neuroscience at the University of Rochester, he is the founding and current Director of the Academic Research Track, an innovative program for medical students that centers on a year-out experience in medical research, often concurrent with Masters degree preparation.

#### **ROBERT GROSS – PAGE 2**

This program is funded by URMC's Clinical and Translational Science Award and he is a member of the grant's Research, Educational and Career Development Directorate. He serves on the design committee for the medical student course "Mind, Brain and Behavior" for which he provides 9 hours of lecture in neuropharmacology. He is the Director of a novel basic science course for fourth year medical students, the month-long "Process of Discovery," in which students design cutting-edge research programs to effect changes in clinical care over a decade. He teaches in AAN

Annual Meeting courses, including the Career Development course. He has developed mentoring programs for residents, fellows and faculty in the Department of Neurology.

He served as an Associate Editor of Neurology® for 8 years, two of which were as Deputy Editor. He is the current Editor-in-Chief of the Neurology® journals.

He is a fellow of the ANA and AAN, and a member of the American Epilepsy Society. Dr. Gross was active in the Epilepsy Foundation of the Rochester, Syracuse and Binghamton regions (currently Epilepsy-Pralid, Inc.), and was a past President of the Board.

He has appeared on the PBS program "Second Opinion" and on local radio shows on the topic of epilepsy.

#### **Awards**

#### 1997

**Buswell Fellow** 

Location: University of Rochester

1987

S. Weir Mitchell Award

Location: American Academy of Neurology

## **KEITH BLACK**

Neurosurgeon

Chairman of the Department of Nuerosurgery and the Director of the Maxine Dunitz Neurosurgical Institute at Cedars-Sinai Medical Center in Los Angeles & holds the Ruth and Lawrence Harvey Chair in Neurosciences & Professor of neurosurgery at Cedars-Sinai Medical Center \*recommended by Dr. David Dodick

Bio/Info Links: <a href="https://en.wikipedia.org/wiki/Keith-Black">https://en.wikipedia.org/wiki/Keith-Black</a> (surgeon) & <a href="https://bio.cedars-sinai.org/black/index.html">https://en.wikipedia.org/wiki/Keith-Black</a> (surgeon) & <a href="https://bio.cedars-sinai.org/black/index.html">https://bio.cedars-sinai.org/black/index.html</a> & <a href="https://www.cpnas.org/aahp/biographies/keith-l-black.html">https://www.cpnas.org/aahp/biographies/keith-l-black.html</a>

Q9			
Second suggestion for a neurologist board member: *Cannot be a member of the AAN Board			
Name:	Keith Black		
Reason for recommendation:	director of the Maxine Dunitz Neurosurgical Institute at Cedars-Sinai Medical Center in Los Angeles, California		
Relationship (if any):	Acquaintance		
Additional comments:	Prolific fundraiser for cancer (brain tumor) research		
Q10			
Please indicate which of the following characteristics, experiences, skills, expertise, or locations apply to your second neurologist member recommendation:			
Excellent communicator			
Access/connections to affluent individuals			
Access/connections to corporations			
Diversity			
Major donor capacity			
Connected to the mission/vision of ABF			
Located in a city of high-wealth concentration (i.e. New York, San Francisco, LA, Chicago, DC, Houston, Dallas, Atlanta, Seattle, San Diego, or Boston)			

**Keith L. Black** is an American neurosurgeon specializing in the treatment of brain tumors and a prolific campaigner for funding of cancer treatment. He is chairman of the neurosurgery department and director of the Maxine Dunitz Neurosurgical Institute at Cedars-Sinai Medical Center in Los Angeles, California.

Keith Black was born in Tuskegee, Alabama. His mother, Lillian, was a teacher and his father, Robert, was the principal at a racially segregated elementary school in Auburn, Alabama; prohibited by law to integrate the student body, Black's father instead integrated the faculty, raised standards, and brought more challenging subjects to the school.

Later in his childhood, Black's parents found new jobs and relocated the family to Shaker Heights, Ohio. Black attended Shaker Heights High School. Already interested in medicine, Black was admitted to an apprenticeship program for minority students at Case Western Reserve University, and then became a teenaged lab assistant for Frederick Cross and Richard Jones (inventors of the Cross-Jones artificial heart valve) at St. Luke's Hospital in Cleveland.

At 17, he won an award in a national science competition for research on the damage done to red blood cells in patients with heart-valve replacements. He attended the University of Michigan in a program that allowed him to earn both his undergraduate degree and his medical degree in 6 years. He received his M.D. degree from the University of Michigan Medical School in 1981.

Career - after serving his internship and residency at the University of Michigan, in 1987 he moved to the UCLA Medical Center in Los Angeles, where he later became head of UCLA's Comprehensive Brain Tumor Program. In 1997, after 10 years at UCLA, he moved to Cedars-Sinai Medical Center to head the Maxine Dunitz Neurosurgical Institute. He was also on the faculty of the University of California, Irvine School of Medicine from 1998 to 2003. In 2007 he opened the new Johnnie L. Cochran Jr. Brain Tumor Center at Cedars-Sinai, a research center named after the famous lawyer who had been Black's patient and supporter.

Black has been a frequent subject of media reports on medical advances in neurosurgery. He was featured in a 1996 episode of the PBS program *The New Explorers* entitled "Outsmarting the Brain". *Esquire* included him in its November 1999 "Genius Issue" as one of the "21 Most Important People of the 21st Century." He has been cited as an expert in reports about whether mobile phone use affects the incidence of brain tumors.

In 1997, *Time* magazine featured Black on the cover of a special edition called "Heroes of Medicine". The accompanying article described Black's reputation as a surgeon who would operate on tumors that other doctors would not, as well as aspects of his medical research, including his discovery that the peptide bradykinin can be effective in opening the blood–brain barrier.

In 2009 Black published his autobiography, co-authored with Arnold Mann, entitled *Brain Surgeon. New York Times* reviewer Abigail Zuger described the book as a "fascinating, if somewhat stilted, memoir". The *Publishers Weekly* review commented that the book "examines racial hurdles he had to leap to become a neurosurgeon" and "alternat[es] incisive writing about incisions with his personal memoir, insightful and inspirational."

## CARMEL ARMON, MD

Chairman, Department of Neurology Yitzhak Shamir (Assaf Harofeh) Medical Center - Zerifin, Tel Aviv, Israel \*Self nominated

Bio/Info Links: <a href="https://www.researchgate.net/scientific-contributions/38714981-Carmel-Armon">https://www.researchgate.net/scientific-contributions/38714981-Carmel-Armon</a> https://pubmed.ncbi.nlm.nih.gov/29807753/

#### **Experience**

Chairman, Department of Neurology - Yitzhak Shamir Medical Center, 2013-current

Leading, managing and developing a multidisciplinary Neurosciences team in a tertiary care center and teaching hospital. Providing inpatient and outpatient care and diagnostic testing, teaching medical students, training Neurology residents, and advancing medical knowledge.

From Snow to Hill to ALS: An Epidemiological Odyssey in Search of ALS Causation.

Journal of Neurological Sciences. 2018;391:134-140.

Ethics of clinical research in patients with ALS: is there a risk of exploitation?

Amyotroph Lateral Scler Frontotemporal Degener. 2018;19:161-166.

Accrued Somatic Mutations (Nucleic Acid Changes) Trigger ALS: 2005-2015 Update.

Muscle Nerve. 2016;53:842-849.

Professor of Neurology - Tufts University School of Medicine, Oct 2004 - Jan 2013

Smoking may be considered an established risk factor for sporadic ALS. Armon C. Neurology 2009;73:1693-1698. An Evidence-Based Medicine Approach to the Evaluation of the Role of Exogenous Risk Factors in Sporadic Amyotrophic Lateral Sclerosis. Armon C. Neuroepidemiology 2003;22:217-228.

Consultant, Massachusetts Department of Public Health, Bureau of Environmental Health: Commonwealth of Massachusetts ALS Patient Registry

Chief of Neurology - Baystate Medical Center, Sep 2003 – Jan 2013

Grew the division from 5MDs and 1 PA to 9MDs and 9 NP/PAs; growth of a large Sleep Medicine and neurodiagnostic program; growth of an inpatient consulting service and multiple outpatient practice sites; establishment of subspecialty programs; development of a system-wide stroke Teleneurology program. Advancement of quality as: Baystate Stroke Medical Director; Co-Chair, Neuroscience Performance Improvement Committee; Chair, Neurology Patient Safety Committee.

Early adopter of reporting within the Medicare Physician Quality Reporting Initiative (PQRI, now PQRS)

**Asst., Assoc., and Professor of Neurology -** Loma Linda Univ School of Med and MC, Aug 1991 – Jul 2003 Medical Director, EEG Laboratory and Epilepsy Surgery Program

Director, Multidisciplinary Clinical and Research Program for Patients with ALS

Director, Neurology Clinical Research Center

Neurologist - Jerry L. Pettis Memorial DVA Medical Center, Aug 1991 – Jul 2003

Evaluation and management of inpatients and outpatients with neurological diseases. Electrodiagnostic testing.

# **Education**

Mayo Graduate School of Medicine - Fellowship in Neuroepidemiology and Neurology, 1988 – 1989

Focus on Amyotrophic Lateral Sclerosis (ALS)

**Duke University Medical Center - 1989 – 1993** 

Duke University Medical Center - Fellowship in Clinical Neurophysiology, 1989 – 1991

Mayo Graduate School of Medicine - Residency in Neurology, 1984 – 1988

Technion - Israel Institute of Technology - MSc, Medical Sciences, 1975 – 1980

**Technion - Israel Institute of Technology - MD**, Medicine, 1971 – 1980

## MERIT CUDKOWICZ, MD, MSc

Director of the Sean M. Healey & AMG Center for ALS
Chief of Neurology at Mass General
Director and the Julieanne Dorn Professor of Neurology at Harvard Medical School
\*recommended by Jane Ransom

Bio/Info Links: Harvard Brain Science Initiative, Harvard Catalyst Profile

Merit Cudkowicz, MD, MSc is an American neurologist, neuroscientist, and studies amyotrophic lateral sclerosis (ALS). Cudkowicz is Julieanne Dorn Professor of Neurology at Harvard Medical School, director of the ALS clinic and the Neurological Clinical Research Institute at Massachusetts General Hospital (MGH) and chair of the Department of Neurology at MGH. Cudkowicz has led several large scale collaborations and clinical trials to test novel treatments for ALS and as of 2020 researches ways to detect early biomarkers of ALS to improve diagnosis.

Cudkowicz was born in Buffalo, New York. Her parents were both immunologists, her father a professor and her mother a research technician. From a young age she knew she wanted to pursue science and ended up studying engineering at the Massachusetts Institute of Technology. She was interested in nuclear engineering at the time so she majored in chemical engineering. By the end of undergraduate degree at MIT, Cudkowicz decided that she wanted to attend medical school instead of a PhD, she stayed in Boston to take a medical degree at Harvard Medical School. She joined the Health Sciences Technology program at Harvard Medical School and became very passionate about neuroscience as well as providing care for patients in the clinic. During her time at Harvard, she also obtained a master's degree in clinical epidemiology through the Harvard School of Public Health. After her medical degree, Cudkowicz completed her internship at Beth Israel Hospital in New York City and then returned to Boston to complete her neurology residency and fellowship at MGH. During her residency, Cudkowicz became the chief resident in Neurology at MGH.

During her residency, Cudkowicz decided to pursue clinical research centered around experimental therapeutics. Since the clinical neurology program at MGH at the time was non-existent at the time, Cudkowicz explored collaborations in order to improve the involvement of academic clinicians in clinical trials for neurotherapeutic innovations. In 1994, she established the Neurology Clinical Trial Unit at MGH. The program has since become the Neurological Clinical Research Institute (NCRI). She is director of the program which organizes patient data for clinical trials for neurological disorders.

Cudkowicz also developed the Northeast ALS Consortium (NEALS) during her residency with partner Jeremy Shefner in 1995. The goal of NEALS is to perform collaborative and academic led clinical trials for ALS. NEALS began with the involvement of 9 academic clinical centers and has since expanded to almost 100 centers worldwide. Cudkowicz has since remained involved in the leadership of NEALS and is co-director of NEALS Clinical Trials Network.

After her residency training, Cudkowicz became a professor at Harvard Medical School. She is now Julieanne Dorn Professor of Neurology at Harvard Medical School, chief of the Neurology Service at MGH, co-director of the Neuromuscular Division at MGH, and director of the Sean M. Healey & AMG Center for ALS at MGH, which she launched in 2019. Her academic research focuses on ALS and she develops novel diagnostics and treatments for patients with ALS and organizes large clinical trials to bring new approaches closer to use in the ALS patient population.

As a principal investigator in the NeuroNEXT Clinical Coordinating Center at MGH which is a part of the National Institute of Neurological Disorders and Stroke's Neurology Network of Excellence in Clinical Trials, Cudkowicz is involved in leading the group to expedite therapy development for neurological disorders. Through this initiative, she launched the first ALS treatment discovery pipeline, the HEALEY ALS Platform Trial, which will promote expedited research for ALS.

- 2019 2019 Ray Adams American Neurological Association Award
- 2018 Achievement in the Professions Pinnacle Award
- 2017 Forbes Norris Award from the International MND Alliance
- 2014 Lou Gehrig Humanitarian Award
- 2009 American Academy of Neurology Sheila Essay ALS award
- 1998 Claflin Distinguished Scholar Award

## **JOHN MORRIS, MD**

Harvey A. and Dorismae Hacker Friedman Professor of Neurology Professor of Pathology and Immunology, Physical Therapy & Occupational Therapy at Washington Univ. Director and Principal Investigator of the Charles F. and Joanne Knight Alzheimer's Disease Research Center \*recommended by Jane Ransom

Dr. John C. Morris is a leading researcher in the fight against Alzheimer's disease. The focus of Dr. Morris' research and practice is Alzheimer's disease and other neurological disorders associated with aging. Specific research interests include improving the diagnosis of early-stage Alzheimer's disease, clinicopathological correlations in dementing disorders, evaluating new drugs for the treatment of dementia, establishing phenotypes for inherited forms of Alzheimer's disease and other dementias, and identifying preclinical stages of Alzheimer's disease by biomarker and neuroimaging studies.

Dr. Morris earned his medical degree from the University of Rochester School of Medicine and Dentistry in Rochester, New York. He completed residencies in internal medicine at Akron General Medical Center and in neurology at the Cleveland Metropolitan General Hospital, both in Ohio, and then completed a postdoctoral fellowship in neuropharmacology at Washington University School of Medicine. Research interests of Dr. Morris include healthy aging and Alzheimer dementia, antecedent biomarkers for Alzheimer disease in cognitively normal older adults to evaluate risk for Alzheimer dementia, and trials of investigational drugs for the treatment of Alzheimer dementia. He also is committed to the understanding and eventually the treatment of Alzheimer disease in all racial and ethnic groups.

Dr. Morris is author or co-author of over 650 peer-reviewed journal articles, 50 chapters and reviews, and 4 books (current h-index 146). Dr. Morris is a member of several professional societies, including the American Academy of Neurology (he is a past member of the Academy's Board of Directors) and the American Neurological Association. He serves on numerous scientific and community advisory boards and is a former member of the Alzheimer's Association National Board of Directors and its Medical Scientific Advisory Council. He has received many honors and awards, including the Lifetime Achievement Award from the Alzheimer's Association (2004); the MetLife Award for Medical Research in Alzheimer's Disease (2004); the Potamkin Prize for Research in Pick's, Alzheimer's, and Related Dementias from the American Academy of Neurology (2005); the Physician-Scientist Lifetime Achievement Award, Barnes-Jewish Hospital Foundation, St. Louis, MO (2005); the Neville Grant Award for Clinical Excellence from Barnes-Jewish Hospital, St. Louis, MO (2006); the Washington University Academic Women's Network Mentor Award (2008); the American Neurological Association 2009 Soriano Lectureship; the 2009 TS Srinavasan Orator, Chennai, India; and the Carl and Gerty Cori Faculty Achievement Award, Washington University (2010). In 2013, he received the Peter H. Raven Lifetime Achievement Award from the Academy of Science of St. Louis and the Washington University School of Medicine Second Century Award. Dr Morris was the 2013 Medical & Scientific Honoree for the national Alzheimer's Association. He is ranked in the top 1% of investigators in the field of Neuroscience and Behavior by Essential Science Indicators database.

# ABF Governance Committee Meeting Schedule – 2021

Date	Place	Begin	Ends
Jan. 25, 2021	Virtual Zoom Meeting	10:00 a.m. ET	10:30 a.m. ET
		9:00 a.m. CT	9:30 a.m. CT
		8:00 a.m. MT	8:30 a.m. MT
		7:00 a.m. PT	7:30 a.m. PT
Mar. 8, 2021	Virtual Zoom Meeting	10:00 a.m. ET	10:30 a.m. ET
		9:00 a.m. CT	9:30 a.m. CT
		8:00 a.m. MT	8:30 a.m. MT
		7:00 a.m. PT	7:30 a.m. PT
Apr. 19, 2021	Virtual Zoom Meeting	10:00 a.m. ET	10:30 a.m. ET
		9:00 a.m. CT	9:30 a.m. CT
		8:00 a.m. MT	8:30 a.m. MT
		7:00 a.m. PT	7:30 a.m. PT
May. 24, 2021	Virtual Zoom Meeting	10:00 a.m. ET	10:30 a.m. ET
		9:00 a.m. CT	9:30 a.m. CT
		8:00 a.m. MT	8:30 a.m. MT
		7:00 a.m. PT	7:30 a.m. PT
June 28, 2021	Virtual Zoom Meeting	10:00 a.m. ET	10:30 a.m. ET
		9:00 a.m. CT	9:30 a.m. CT
		8:00 a.m. MT	8:30 a.m. MT
		7:00 a.m. PT	7:30 a.m. PT
Aug 9, 2021	Virtual Zoom Meeting	10:00 a.m. ET	10:30 a.m. ET
		9:00 a.m. CT	9:30 a.m. CT
		8:00 a.m. MT	8:30 a.m. MT
		7:00 a.m. PT	7:30 a.m. PT
Sept. 20, 2021	Virtual Zoom Meeting	10:00 a.m. ET	10:30 a.m. ET
		9:00 a.m. CT	9:30 a.m. CT
		8:00 a.m. MT	8:30 a.m. MT
		7:00 a.m. PT	7:30 a.m. PT

Nov. 1, 2021	Virtual Zoom Meeting	10:00 a.m. ET	10:30 a.m. ET
		9:00 a.m. CT	9:30 a.m. CT
		8:00 a.m. MT	8:30 a.m. MT
		7:00 a.m. PT	7:30 a.m. PT
Dec. 13, 2021	Virtual Zoom Meeting	10:00 a.m. ET	10:30 a.m. ET
		9:00 a.m. CT	9:30 a.m. CT
		8:00 a.m. MT	8:30 a.m. MT
		7:00 a.m. PT	7:30 a.m. PT