

COUNTDOWN TO BOSTON

6 DAYS



## "F" is for Child Neurology Foundation

"F" is also for "Friends." I first met Amy Brin over coffee at an AAN meeting in Philadelphia back in 2013, before she became Executive Director of the Child Neurology Foundation. The coffee has never stopped flowing and the friendship has never stopped growing. Like a true friend, Amy has always put out the open offer, "Whatever I can do to help, let me know." As the meeting draws closer and I find myself drowning in deadlines and details, I took her up on her offer, grateful for the extra time it buys me, but more importantly, knowing no one could tell this tale better than she (certainly not me). So, with your kind indulgence, Dear Reader, I will flip "G" and "F" and let Amy take it from here.

Until tomorrow ("G is for Generations")  
Roger

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No walk down memory lane is complete without including memories shared with your favorite partners. One of the most distinct relationships CNS has shared in its first 50 years is the one with the Child Neurology Foundation (CNF). And for CNF, there is no greater relationship than the one we share with CNS.

Founded 30-years after CNS, CNF began its service to the child neurology community in 2001 through the leadership of Dr. Kenneth Swaiman. Dr. Swaiman saw the opportunity for greater philanthropic activity to help the child neurology profession and joined with titans like Stephen Ashwal, MD; Donna Ferriero, MD; Gary Goldstein, MD; John Pellock, MD; and Alan Percy, MD to set the course for this new endeavor. Under these pioneering leaders – and with partners like Dr. Roy Elterman of **Pediatric Epilepsy Research Foundation** – CNF began to provide research grants to early investigators. Like any "younger sibling," CNF learned to crawl and then walk during these formative years... and struggled find its identity, often "trying on" various roles with programs in disease awareness or medical student outreach. These "play periods" brought about confusion regarding CNF's identity. What is CNF's role in the child neurology sector? And what is its relationship with CNS? In truth, by the time CNF reached its adolescence – year 13 of operating – it was in chaos, with great uncertainty and internal strife.

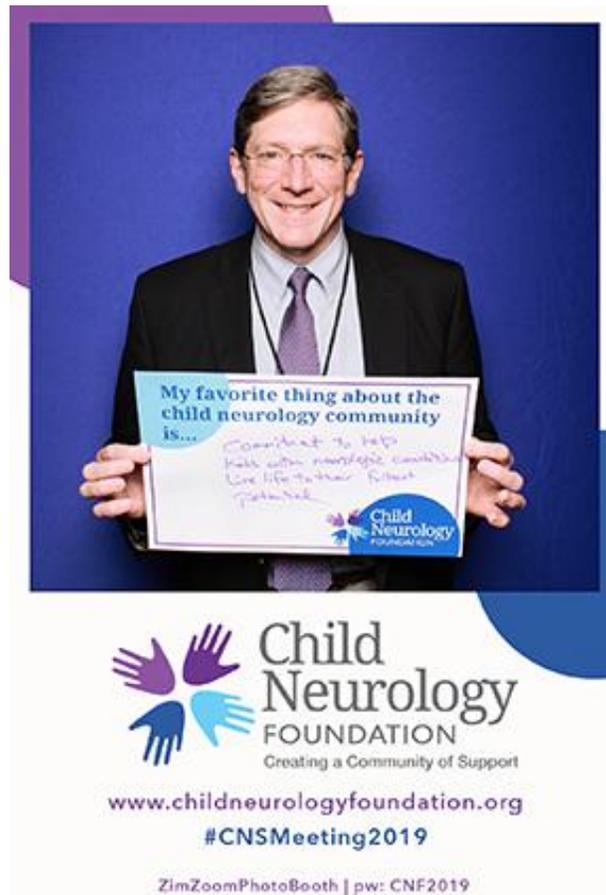


For all of us trained in Pediatrics, we are taught to offer reassurance and preach the importance of consistency, stability and order – especially in the time of change (i.e. adolescence). Enter W. Donald Shields, MD: the ultimate “parental figure” who was named CNF President in 2012. With Don at the helm, truth was seen, and truth was spoken. Difficult but revolutionary decisions were made that chartered a new course for CNF. Don’s vision signaled the critical need for a “hub” – a connective center – for the child neurology sector that would bring caregivers, physicians, allied health professionals, researchers and industry partners together for the first time. This center would be collaborative, with impeccable values anchored in stewardship and “doing the right thing first.” It would be innovative in its operations – utilizing for-profit business mechanisms to avoid falling victim to the typical fiscal and management lability seen in some non-profits. It would be courageous in tackling complex, gnarly problems that often reside in the shadows of our community yet *are the very issues that impede both families and physicians from attaining/providing quality care.*



The Child Neurology Foundation rebranded in 2015: *to create a community of support.* As true

with any bold, decisive and needed act of leadership, Don's efforts were profoundly noticed by his child neurology colleagues, and immediately as well as in the years to come, his *comrades in arms* stepped up to serve the vision Don championed. CNF continues to be stewarded by some of the sector's most compassionate, daring and esteemed leaders: Jan Brunstrom, MD; Lawrence Brown, MD; Bruce Cohen, MD; Sidney Gospe, MD; Shaun Hussain, MD; Shafali Jeste, MD; Tom Langan, MD; Bennet Lavenstein, MD; Ken Mack, MD; Jonathan Mink, MD; Anup Patel, MD; Phillip Pearl, MD; Scott Perry, MD; Scott Pomeroy, MD; Nina Schor, MD; Ann Tilton, MD; William Trescher, MD; Amy Waldman, MD; and Mary Zupanc, MD. These CNS members have been part of CNF's Board of Directors alongside allied health professionals, business leaders and parent advocates for the past seven years. Together, their leadership provides a unified vision for how an organization can leverage multi-stakeholder expertise, insights and resources to strategically approach issues that affect the entire child neurology landscape. They operate from a position of unity: *that we are all child neurology.*



Through their deep commitment and excellence in leadership, these collaborators have rewritten the *Rising Tide* of CNF as the only patient-facing advocacy organization in the neurology space that was started by and actively governed by physicians. Today, CNF drives in the areas:

1. **Education** (patient and provider), including topics in **transition of care, shortening diagnostic odyssey, SUDEP, genetic testing, telehealth** and **behavior management**
2. **Support**, including **resource navigation, emotional support** for caregivers and **financial grants**
3. **Research**, including **grants** and investment technology to bring unique **clinical decision support system to child neurology**
4. **Advocacy**, federal, state and community levels

And the results speak for themselves:

- Annually, serving hundreds of thousands of patients/ families
- Serving families in all 50 states and over 70 countries
- Working in over 90 disease states within the child neurology spectrum
- Developed over 100 patient education materials
- Providing \$250K in financial relief to families during 2020 COVID-19
- Providing \$4.1M in research grants to CNS members
- Annual hosting of symposium at CNS Convention with growing numbers of attendees (125 in 2015 to >350 in 2020)

As CNS celebrates its' 50th anniversary in 2021, CNF celebrates our 20th. Proud to have grown out of our awkward years of adolescence, we now stand confidently in our identity and in our revised mission statement: *to serve as a collaborative center of education, resources, and support for children and their families living with neurologic conditions and facilitate connection with medical professionals who care for them.*

We look to our **Next 20!** years, grateful to serve beside our closest partner, CNS. We want to hear the child neurology profession's greatest challenges and needs and understand how we can be of service to you. We want to celebrate your gains. We want a brighter tomorrow for the child neurology profession: one that showcases the unique expertise you are distinctively trained to bring to our country's most vulnerable - our medically complex children. We envision a future where you have the resources and support you need to not feel burnt out or overwhelmed by the administrative requirements hitting your clinical practice. One where the research innovations that are driving evidence-based best practices towards new treatments and cures are able to be seamlessly absorbed into your craft. We, at the Child Neurology Foundation, see this future because it is only THIS future that allows our vision – *that all children living with neurologic conditions will reach their full potential* – to be realized.



Let us be clear, the Child Neurology Foundation is laser focused on grabbing that better tomorrow for all children and families living with a neurologic condition, BUT we can only do that when we are all working as one. We are here to support you, CNS, and we salute all your members – the newest, the most revered, the ones that have yet to make a CNS meeting, the ones who will share their expertise next week with us in Boston, the ones who are feeling burnt out, and the ones who know they belong. We are here for you. Let us know how we can help you in the care you provide to our community's children and their families.

We look forward to seeing you in Boston and toasting your 50th years strong!

Warmly and with great respect,  
Amy E. Brin, MSN, MA, PCNS- BC  
CNF Executive Director/ CEO

[www.childneurologyfoundation.org](http://www.childneurologyfoundation.org)  
Join our Newsletter!

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### On-line Registration is Open!

Registration is now open for the long awaited 50th Golden Anniversary Meeting of the Child Neurology Society in Boston. Registrants attending this milestone meeting live and in-person in Boston will want to register early (some sessions are limited and reservation-only). You may also use this link to modify your registration as

### 2021 CNS 50th Annual Meeting

For more information, click button below.

[Click for More Info](#)

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needed, including switching from live in-person to Virtual, or vice versa.

[Click to Register](#)

