

COUNTDOWN TO BOSTON

35 DAYS



"N" is for Neurobiology of Disease in Children (NDC)

Growing up in the 60s and 70s, I imagined the easiest paying gig anyone could ask for was Ed McMahon's job playing sidekick to Johnny Carson. You put a tie on, make sure your shoes were shined, sit up straight like your mother taught you, smile when you think the camera is on you, and laugh with faux gusto any time Johnny gave you "that look" or said something remotely funny. How tough was that?

In 2001, after 13 years of stressing out at the beginning of each CNS Annual Meeting, I not only found a way to take the stress out of those Wednesday mornings, I discovered that, quite by accident, I had come across a paying gig that made "Big Ed's" job look like a 12-hour shift in a coal mine. All I had to do was make sure the AV crew had the microphone turned on when Bernie Maria climbed onstage to introduce that year's NDC Symposium, then show up 10 hours later at the Welcome Reception to ask him "How'd it go?" His answer was always "great!". Why wouldn't it be? It was his show and "great" was his MO.

I can't tell you how relieved I was, two weeks into the 50-Day Countdown to Boston, to wake up this morning and realize it was Wednesday. A light bulb went off: Why change the magic, the secret sauce that got you through 20 years of high-stress Wednesdays?

So, with that in mind, I'll just say the two magic words and get out of the way: "Here's Bernie!"



Reflections on Neurobiology of Disease in Children (NDC) Symposia (1998, 2001-2020)

by Bernard L. Maria MD/MBA (Principal Investigator)

The field of child neurology has grown exponentially, due in part to our growing understanding of

molecular neuroscience, brain pathology and genetics; but also due to improvements in neuroimaging and personalized medicine. Given the impressive rate of discovery in the field of child neurology, the ongoing challenge has been to translate this information into improved clinical outcomes and life-saving therapies that can be used by every child neurologist; a task that requires the cooperation of basic scientists, child neurologists and clinicians from many disciplines, lay organizations, and governmental agencies.



Starting in 1998 with a NIH-funded satellite symposium (Joubert syndrome) at the Annual Child Neurology Society Meeting held in Montreal, Canada, and then continuously funded through four 5-year R13 NIH grants from 2001 through 2020, the Neurobiology of Disease in Children (NDC) symposia played an important role in child neurology. An annual in-depth forum focused on spreading the most up-to-date information on the clinical aspects, pathogenesis, therapeutic targets, translational opportunities, and future directions for a given neurological disorder affecting children. The attendance has included speakers and moderators who are among the most preeminent physicians and scientists, young investigators and scholars at different stages of career development, lay organizations and associations who are champions for families of children affected from a variety of conditions, officials from the NIH, and members of the Child Neurology Society who then return to their respective communities with knowledge, values, skills and ideas on ways to move the field forward.



It is difficult to fully measure the impact of a conference or symposium, especially over more than 20 years. In fact, the same difficult question could be asked about the impact of the Annual Child Neurology Society Meeting over the last 50 years. One of the interesting things about our medical societies (CNS, ANA, AAN, APS, SPR, etc) is that they are centered on the needs of the respective practitioners (e.g. pediatricians, neurologists, ophthalmologists, geneticists, etc) who are members of their respective society. However, moving the field forward on any disease requires input from multiple clinical and scientific disciplines that may not regularly attend respective society meetings other than their own. I would say that the principal innovation of NDC has been to include multiple disciplines in partnership with the NIH, respective foundations and associations, and the Child Neurology Society. In fact, while child neurologists were always among those speaking and moderating, they could easily represent the minority of speakers in the day-long symposium. NDC was “born” and then nurtured by the Child Neurology Society because

of the “appetite” among child neurologists for an in-depth discussion or as former NINDS Director Dr. Story Landis used to say “soup to nuts” on a specific disorder. NDC was a home for communities of caregivers (Foundations/Associations) to build awareness and advocate for attention and research on their specific condition (Neurofibromatosis, Leukodystrophy, Tourette syndrome, others). NDC featured overlapping and complimentary multidisciplinary expertise and defined research priorities with active input from the child neurology community. NDC supported career development of many scholars and promoted interactions within the child neurology community, what I have come to call the “seeds of the field.” NDC motivated partnerships between child neurology, communities of caregivers, and Federal funding agencies to move our field forward.



The proceedings of NDC over 20 years included hundreds of publications of both original and review articles, as well as summary podcasts posted to the meeting’s website (neurobiologyofdisease.com). I am especially proud to have catalyzed new collaborations among speakers (over 200 papers as first-time publications co-authored by NDC speakers), moderators, panelists and over 250 young investigators, 43% of whom were minority scholars.

As I reflect on the last 20 years of NDC and what Roger Brumback said about NDC after its first 10 years, I see the educational value of NDC much like I see the contributions from assembling a medical textbook. In 1999, I edited the first edition of *Current Management in Child Neurology* that ultimately had four published editions. Believe it or not, the first edition was the first medical textbook with a CD ROM! The purpose of the book was not that different from NDC in that both had the overarching goal of assembling knowledge from the experts and formatting it for an efficient and forward-looking clinical practice to better serve our patients. The advent of the internet, rapid pace of advances, shortened turnaround time needed for updates, evolution of internet libraries (Medlink Neurology, Up-to-Date, others), ease of access of information from multiple sources, and other important generational trends, made the practical textbook, *Current Management in Child Neurology*, largely obsolete. When thinking about assembling a 5th edition, marketing analysis showed that the targeted segment of pediatricians, neurologists, and trainees had moved onto internet sources of information.



Like the medical textbook, I believe that NDC needs reinvention and innovation. The pandemic has forced rethinking our continuing medical education and while virtual connectivity has clear advantages, it cannot create the same 'human hub' of togetherness for interaction and collegiality that characterized in-person NDC. The audience has changed over the last 20 years and the younger mix has learned in ways that are quite different than boomer and silent generations. The values (including scholarly pursuits) of the four active practicing generations of pediatricians and child neurologists are probably still quite different from one another so how to incorporate 'mechanisms of disease' and 'translational opportunities' into future NDCs should probably be revisited. At a very basic level, advances in genetics have complicated matters and using leukodystrophy as an example, there were over 40 new leukodystrophies discovered between the original NDC symposium on the topic in 2002 and the updated one in 2017. In 2001, there were no clinical trials in neurofibromatosis but there were over 50 open clinical trials in 2016. While all of this is a measure of progress, it makes a future NDC symposium on NF or leukodystrophy potentially quite problematic. With over 5000 single gene disorders and 3500 conditions affecting the developing nervous system, what should the next series of NDC meetings address?



A more pragmatic challenge has been funding for NDC. While the meeting costs approximately \$100,000 to hold in-person annually (AV costs, travel, personnel), no more than \$35,000 to \$50,000 was provided by the NIH. With audiovisual costs alone hovering around \$35,000 in recent years, finding co-sponsors to offset cost has been difficult because fewer Foundations/Associations have the requisite level of funding. While the Child Neurology Society has graciously served as cosponsor, it is not enough to make the meeting feasible in the usual in-person format. If anyone picks up the mantle to lead NDC into the future with the NIH (NINDS/NCATS) as the major sponsor, I envision a hybrid meeting that assembles speakers and panelists to interact in person with one another and young investigators and a small in-person audience of child neurologists and perhaps a larger virtual audience of child neurologists who could provide the requisite funding for NDC to flourish.

It has been a privilege to chair NDC since its inception. I have learned a great deal that has directly served the children in my practice as well as supporting my colleagues and mentees, especially with in-person interactions. Thank you for your support of NDC over the years and for

recognizing some of what it has contributed in over 20 of our society's wonderful 50 years.

Thanks,
Bernie

Until tomorrow (The Letter "O")
Roger

Roger Larson, CAE
Executive Director

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 will also want to book hotel rooms ASAP. A link and access code to the Sheraton Boston Hotel will be included in your registration confirmation email.

[Click to Register](#)

2021 CNS 50th Annual Meeting

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