

Dr. Barohn's remarks for Dr. Griggs's  
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One of the greatest gifts you can receive when starting an academic career is the gift of having a good mentor. I was fortunate to have several great mentors. At Ohio State University, Jerry Mendell was my primary mentor along with John Kissel and Zarife Sahenk. But who I call my long-distance mentor from the beginning was—and continues to be—Berch Griggs. Jerry introduced me to Berch at the outset of my fellowship, and he—as many of us have experienced—became an ever-present figure in my academic career.

My first interactions with Berch were at the American Academy of Neurology annual meetings in the 1980s. I particularly remember the early years of the neuromuscular after-dinner seminar that Berch, Jerry, and Bob Miller led. As I recall, because of my junior rank and just having finished the Mendell gauntlet fellowship, Berch frequently called on me to figure out a case as my baptism by fire. I think I was much smarter then, and my goal was to not disappoint my mentors with a wrong answer.

Let me tell you about five gifts that I have received from Berch:

The first involved that early AAN experience, when I presented a case of a Miyoshi distal myopathy. We were just starting to talk about this phenotype in the United States, a decade before the molecular genetics were discovered. Berch and Bob said they both had cases, and it was HIGHLY suggested by Berch that I write up all our cases for publication, which I dutifully did—and quickly! Berch sent me not only clinical information, but also old-fashioned black and white photographs of his patient who made it into the paper. The paper was published in *Neurology*. I originally had the title “Miyoshi myopathy—a series of U.S. cases.” Bob Miller, who became another long-distance mentor, advised me that we should not call diseases by a person's name any longer, and we should use the more descriptive term, “autosomal recessive distal muscular dystrophy.” I went along with Bob's advice, and Berch weighed in, although I don't recall how—I guess you probably agreed with Bob. But I still think we should've called it Myoshi myopathy. At any rate, this was an amazing opportunity for a 30-year-old, freshly trained neuromuscular neurologist still in the Air Force to get a chance to write a paper with superstars in the field from the east and west coasts.

The second gift came a few years later, when I believe Berch was the president of the American Academy of Neurology. He brought to our attention that the neuromuscular neurologists did not have a formal section in the academy. He wanted that to be corrected. He asked me to begin the process of starting a neuromuscular section, which I dutifully did—and quickly! Petitions were signed, and the section was launched. I served as the inaugural chair of the section. I believe the neuromuscular section has played a key role in shaping the field of neuromuscular disease.

The third gift also involved the AAN, also while Berch was in a leadership position at the academy. He placed me on the annual meeting subcommittee which planned that next year's AAN meeting. This was really the first time I was able to meet neurologists outside the field of neuromuscular disease, and the first time I interacted with AAN leadership.

The fourth gift came years later when Berch asked me to be his wingman, otherwise known as co-PI on the big NIH Consortium for the Investigation of Neurologic Channelopathies (CINCH) project. This was really a career-changing experience and allowed me to work with academic neurologists not only across the U.S. and Canada, but also across Europe. I was able to establish close relationships with colleagues in England (Mike Hanna and Mary Reilly) and Italy (Valeria Sansone and Giovanni Meola). He had me attend the twice a year rare disease consortium meeting. This allowed me to meet with successful academics in medicine that were not neurologists. And it was my first real contact with insiders at the NIH in other institutes that extended beyond neurology. This helped me greatly in my later mission to get a Clinical Translational Science Award (CTSA) grant.

Then, to leverage the CINCH natural history infrastructure study, Berch HIGHLY advised me to submit an ROI application to the FDA Orphan Products Division to study mexiletine for non-dystrophic myotonia. I dutifully did—and quickly! We got this funded on the first submission. The study, as you know, showed that mexiletine worked dramatically in these rare disorders. Not only did we get this paper published in *JAMA*, but even more importantly, I believe it has had a major impact on how patients with non-dystrophic myotonia are cared for.

A fifth of Berch's huge gifts to me was to encourage me to take on leadership roles within the Muscle Study Group, which he began in the late 1990s. I dutifully did this as well. Berch asked me to be his co-chair while he was the chair of the organization. Subsequently, for more than 10 years, Mike Hanna and I have been the co-leaders of this amazing organization of academic neuromuscular neurologists and industry partners. Assembling old and new members of the group, which we now call the Neuromuscular Study Group or NMSG, is the highlight of my year and truly has become one of the highlights of my career.

In addition to always giving sound advice, after working with Berch for a while, you begin to ask yourself whenever you are about to make big decision: “What would Berch do?” And, like many of us, I can honestly say that I am sure I would have had a very different, less-fulfilling and less-successful career path without the guidance and friendship of Berch.

Let me ask for a show of hands. How many in the room have had Berch help them with a manuscript? How many have had Berch’s help on a grant? How many of you have had Berch give you career advice? How many of you have had Berch give you advice on how to run an organization? By my statistical analysis, I think most everyone in this room has raised their hand, with a P value of less than 0.01. I am thrilled to be here to be part of honoring Berch at this point in his career, which I know is far from over. I consider this a pause... for a celebration of all that you have achieved.

Berch, being here at this event means a great deal to me. I am so glad that I can be part of this celebration and honor your contributions to the field of neurology, but also the immense impact you have had on the careers of so many.

Dr. Griggs gave a wonderful address to the audience at the Festschrift. I want to tell you about the lists he gave us as words of advice. He called the words of advice “Hanging Ten” and had a picture of a surfer “hanging ten.” I don’t think Dr. Griggs is a surfer, but he was making the analogy of how to be top of your game. He showed a slide titled “Conclusion: “Hanging Ten” with ten points:

- 1) Pick a [rare] disease - 20,000 possibilities (if you go rare);
- 2) Hang out your shingle - a specialty clinic for patients;
- 3) Find collaborators;
- 4) Identify international collaborators;
- 5) Organize a meeting of current and future experts;
- 6) Work with/start on advocacy organizations(s);
- 7) Include non-clinician basic scientist(s);
- 8) Engage mentee(s);
- 9) Write a review/position paper;
- 10) Funding?

Then Dr. Griggs gave another ten suggestions for funding, with a slide titled “Conclusion: ‘Hanging Ten’: Funding.” The ten funding suggestions were: 1) Advocacy organization; 2) Pharma support: Pharma-initiated, investigator-initiated clinical trials; 3) Federal: NIH, FDA (for credibility); 4) Intellectual property: Patent the treatment before publishing; 5) Philanthropy - do generous things; 6) Data use agreements - Rochester’s strength (Kim Hart); 7) NY State funding - “members items”, “special initiatives”; 8) Collaborate with others for grant support; 9) NIH R-13 grant to support meetings; and 10) practice income - only for expenses of seeing patients. I thought these words of advice were outstanding and I wanted to share them with the readers of the RRNMF NM J. I asked Dr. Griggs if I could have his permission to share them and he agreed.