



Building a Strong Future for NAF

Update from Executive Director Joel Sutherland

As you can see by the picture, it was time to bring out the props at this year's conference. These particular props are easy to interpret; it is time to build.

So, the questions that come to mind are: what are we going to build, why are we going to build it, how are we going to build it, and who is going to do the building? All good questions!

What Are We Going to Build?

We are going to build the infrastructure of the NAF. "Building the infrastructure" means we need to attract professionals across multiple disciplines to join our efforts across the country. This effort is not just about raising more funds; it is also about building more awareness about Ataxia and growing the NAF team. The

effort will also provide for better and faster communication between our support group leaders, families and medical community and the national office. Raising funds, building awareness and energizing our community will be the result of these efforts.

Why Are We Going to Build NAF?

The ALS Association with an estimated 20,000 people living with ALS in the US has approximately 40 chapters across the country. In 2015 those chapters raised \$23.4 million dollars. The Leukemia and Lymphoma Society with 170,000 people living with these diseases combined have more than 60 chapters in the country generating more than \$231 million. The Cystic Fibrosis Foundation, with 28,000 CF patients in the US coordinate 72 chapters to generate more than \$105 million each year. In contrast, Ataxia affects approximately 150,000 people in the US, yet NAF has remained stable with one office and generated \$1.6 million in 2015. You have to agree, it's time to build! We're going to build it because you, our families, deserve a stronger organization working for you.

How Are We Going to Build NAF?

The fact is we need to start generating more unrestricted funds so we can use those dollars to build the infrastructure. What are unrestricted funds? Unrestricted funds are any dollars that come to NAF that are not limited to a particular use. Unrestricted funds allow NAF to build the infrastructure that is needed for growth, then we too can start raising the dollars our research community needs to get us first, to a treatment and then a cure. Without a sincere, coordinated effort to build the NAF, we will not be able to bring together the resources needed to find a cure at the speed we all want.

Who Is Going to Build NAF?

Now to the last and most important question, who is going to do the building? The answer is simple. All of us are going to build the NAF! Using cooperative efforts between the Board of Director's forward-thinking strategic plan, NAF staff's focused efforts, utilization of business partnerships, and an active and motivated base of families and supporters, we can exponentially increase NAF's ability to spread awareness and fund research.

So, throw on your hardhats, strap on your safety goggles and put on your work gloves. I hope you'll join us in building the NAF!

Joel Sutherland
Executive Director