

## Voluntary Health Leadership Conference Benefits NAAF



Every year when our Board and staff members attend the National Health Council's Voluntary Health Leadership Conference we learn more that benefits NAAF. We have become a better organization from the knowledge gained at this conference and from our membership in the National Health Council.

The National Health Council, which is made up of more than 100 health-related organizations, is the only organization that brings together all segments of the health community to provide a united voice for the more than 133 million people with chronic diseases and disabilities as well as their families and caregivers. Patient organizations have to meet 41 tough good governance standards in order to be members.

This year Board member Bob Flint and staff members Jeanné Rappoport and Vicki Kalabokes attended the NHC leadership conference in Fort Myers, Florida.

## The National Institutes of Health as a Partner in Therapeutic Development

The Opening Keynote Address by Francis Collins, MD, PhD, gave us new insights into the research being conducted at the largest research organization in the world, the National Institutes of Health (NIH). Dr. Collins was the lead investigator in charge of mapping the human genome, which was accomplished in a shorter period of time and at less cost than was proposed. As the Director of the NIH since 2009, he is now trying to accomplish more there with dwindling resources. Any cut in the NIH budget affects all medical research.

There are new happenings at the NIH that should help with NAAF's Treatment Development Program: Dr. Collins told us that the NIH is trying to get more funding for Orphan Diseases (alopecia areata totalis and alopecia areata universalis are categorized as such), and there is a new NIH/FDA Joint Leadership Council to help reach that goal.

A new center has also been created—the National Center for Advancing Translational Sciences (NCATS)—to make the NIH more of a partner in therapeutic development.

## Solutions Offered by the Modern Cures Act

Marc Boutin, Vice President of the National Health Council, discussed the Modern Cures Act, a bill we are trying to introduce in this session of Congress. This act, which has the support of pharmaceutical companies and patient advocacy organizations, addresses the unmet need of treatments for many diseases, including alopecia areata. If this act passes Congress, it will help the Alopecia Areata Treatment Development Program tremendously.

### THE MODERN CURES SOLUTION:

1. Ensures that science not the law drives the development of new therapies (lack of a patent should not be a barrier)
2. Promotes targeted therapies
3. Guarantees immediate access to FDA-approved diagnostic tests
4. Rationalizes the reimbursement system

## Investigating New Medical Devices

Jeffrey E. Shuen, MD, JD, Director of the Center for Devices and Radiological Health, Food and Drug Administration (FDA) gave us insight into how to access new technologies. NAAF is investigating several new technologies as part of its Treatment Development Program, so this presentation was very timely.

Medical devices have three classes of risk:

- Low (such as a tongue depressor), which do not need studies
- Medium, which have a significant impact on patient care but would not be likely to cause direct serious injury and their safety and risk is easily calculated
- High, which need clinical studies

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When looking at new technologies and devices there has to be a reasonable assurance of effectiveness. He suggested that we become involved with DARPA, the agency overseeing the engineering and development of devices at the Department of Defense.

## Patient Advocates as Drivers of Drug Development

Timothy Coetzee, PhD, Chief Research Officer at the National Multiple Sclerosis Society (NMSS), discussed how patient advocates like NAAF can be drivers of innovation in drug development.

He talked about how the NMSS formed Fast Forward, a drug development initiative, as a venture capital effort and subsidiary of the society. There are two boards, but they are integrated on regular science and drug development. They also align academic and drug company representatives.

They have due diligence, contracts, intellectual property, and life sciences agreements. This program has increased their donations and accelerated their drug development.

Fast Forward acts as a venture capital firm and invests in companies in early stage development. This creates research networks that advance translational science and it moves faster. Companies need medical expertise and access to patients.

Any cuts in the Food and Drug Administration (FDA) funding will hurt new drug development for our patients.

## Succession Planning

There were also presentations on the “Ropes of Succession Planning,” which were very timely. NAAF has been updating its succession plan for senior staff and Board officers, and this input was very valuable.

## Emotional Branding

We also had presentations reviewing how organizations implement new emotional branding, like “Go Red for Women” by the American Heart Association.

## Networking and Breakout Sessions

There were also breakout sessions attended by the volunteers and staff of all the groups to discuss issues of concern. ■

## A Goodbye from Our VP of Communications: Lisa Butler



### DEAR FRIENDS:

It is with a heavy heart that I announce my departure from the National Alopecia Areata Foundation staff. Though I am excited and eager to take my next step professionally, it is important for me to let you know how fulfilled my life has been working for this cause for the past 11 years.

Through NAAF, not only did I gain practical skills and worldly experiences that made me the professional I am today, but I inherited second and third families comprised of my coworkers at the organization as well as each and every individual that I had the privilege to know and ultimately call my friend. For me, the motivation to succeed at NAAF came easily; I was inspired to make life better for everyone in my extended family, to bring a smile to a child's face and to help dry the tears of a mother.

Though I will not be seeing you at upcoming conferences, meet & greets, and special events, I am only an email away. I still think of you all and would love to keep in touch. Thank you for being such a huge influence in my life. Working for NAAF will always remain one of the high points in my life—and much of that is because of you!

Love, Lisa

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## NAAF Welcomes Interim Communications Director



Joe Della Cella joins NAAF as the interim Director of Communications. He will be managing all of NAAF's social media and media relations. Prior experience in the field includes being a producer at KNBR Radio, and a Media Relations Assistant for the Emerald Bowl at AT&T Park. Joe is a native of San Francisco, where he earned a Bachelor of Arts in Communications from San Francisco State University. After graduating, he obtained a Master of Arts in Sport Management from the University of San Francisco where he also served as an assistant coach on the school's baseball team.