National Alopecia Areata Foundation (EAIN #1484)

National Alopecia Areata Foundation Annual Patient Support Conference
Project Lead: Dory Kranz, MA
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Summarize the following: 1) project methods, 2) key project findings, and 3) interpretations of the relevance of findings to patients/stakeholders, clinicians, and/or health care systems:

- NAAF’s Annual Patient Support Conference brings together patients, partners, physicians, researchers and industry, providing an ideal forum for patient partner engagement, support and community leadership development. Individuals with alopecia areata and their loved ones gather together to share their experiences with one another and to learn directly from leading scientists and medical professionals about the latest research efforts, treatment options, and opportunities for patient engagement. The conference provides support to parents and families of people with this disease.
- The 2015 Patient Support Conference was held Thursday, July 25-Sunday July 29th at the Hyatt Regency, Orange County. The four day conference included presentations from the leading experts in alopecia areata research and clinical care, child development specialists, support sessions covering 19 topic areas, panel discussions, patient partner guest speakers, panel discussions, focus groups, exhibitor displays and community building and networking activities.
- 688 people attended the Conference, coming from 40 U.S. states and eight foreign nations. Of that total, 306 were “VIPs” - enjoying their first NAAF Conference.

Describe the impact and outcome of the project as it relates to patients/stakeholders:

- The Conference is referred to by many in the community as ‘the treatment until we find a treatment”. The Conference has an immediate impact on attendees’ sense of well-being as they find they are not alone, there is support, there is research and there are many ways to be involved.
- NAAF distributed a Conference Evaluation Survey to our patient stakeholders and 62 were returned completed. Respondent rated their experiences on a scale of 1 (excellent); 2 (good); 3 (fair); or 4 (poor). Here is a summary of responses from our patient/stakeholders regarding impact and outcome.
- The overall conference experience average rating was 1.3. Patient/Stakeholders commented on the value of the conference and the impact it had on their lives:
  “This was our first NAAF conference and it was truly a life-changing experience for my 9 ½ year old daughter. Although she knew that there were others who also suffer from alopecia areata, actually seeing the other kids, especially girls her age who also have hair loss was empowering in an extremely profound way. Although she still hates that she has AA, we see a difference in her confidence since coming home.”
- The Conference is also a place where patient stakeholders can share insights and information with researchers and clinicians into the types of treatments that would be meaningful to them. A key objective is to build bridges of understanding between patients and the researchers and clinicians who design and deliver treatments.
- A successful example of this came out of the Health and Research Ambassador Program which was piloted by a patient stakeholder, Angela Rodgers, earlier this year. When she entered college and lost her hair, this brought about a time of emotional turmoil and she sought the help of a psychiatrist. It was very helpful. She wished that when she was a young person just
diagnosed with AA, that her dermatologist had talked to her about the emotional component and given her a referral to seek psychological help if she needed it. This experience led her to begin the HARA Pilot.

- The HARA pilot focused on increasing awareness of alopecia areata, resources available to patients with alopecia areata and the medical professionals who care for them, and asked medical providers to consider mental health screening and referrals based on the high prevalence of psychosocial distress in those with alopecia areata.
- Research shows that there is a substantial psychological and emotional burden that alopecia areata has on individuals and families. NAAF is an excellent resource for patients and medical providers to address this component of the disease in addition to providing up-to-date information on clinical trials and educational events. NAAF seeks to ensure that every individual affected by alopecia areata has the support they need to live a healthy life with this chronic condition.
- Over the course of 7 months, four HARA presentations were given (3 in-person and 1 by telephone). The in-person presentations were co-lectured by Angela Rodgers and UC David Professor and Psychiatrist Dr. Nathan Fairman.
- Over 65 dermatologists received in-person presentations. Fourteen new physicians were added to the NAAF database. Over 100 dermatologists received the Official NAAF Statement to Medical Providers via email which provides information about NAAF and recommends that medical providers consider giving their patients a mental health evaluation when they present with alopecia areata. Presentations were completed or scheduled at all major academic institutions in northern California including University of California Davis, University of California San Francisco, and Stanford University Medical Center in addition to health care systems such as Kaiser and Sutter Health.
- During these presentations, all dermatology residents were given post-presentation surveys and the responses were overwhelmingly positive. Out of 30 residents (UCD School of Medicine and UCSF School of Medicine), 100 percent of them felt that they had learned about the relationship between mental health and dermatology as well as the prevalence of mental health indications in dermatology. They all felt more capable in identifying emotional distress in their patients and were engaged during the presentation. Most of the residents (17 of 30), increased their mental health in dermatology knowledge as a result of the presentation. Ninety percent (27 of 30) of the residents felt comfortable in discussing mental health resources with their patients after the presentation. Ninety seven percent (29 of 30) of the residents recommended that the lecture should be incorporated into the standard resident didactic curriculum.
- When this information was presented at the Annual Conference, there was overwhelming support for its continuation from attendees. Several patient/stakeholders expressed the desire for a more holistic approach to treatment that included information and resources from their dermatologist about mental health services and support.

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1 Prevalence of Psychological Disorders in Patients with Alopecia Areata in Comparison with Normal Subjects, Shahin Aghaei, Nasrin Saki, Ehsan Daneshmand, and Bahare Kardeh, March 2014
Angela demonstrated the ability to make an impact as a patient stakeholder and inspired many others to want to do the same, whether through the HARA Program, as a Legislative Liaison, starting a mentoring program or by participating in research.

Discuss final project accomplishments and challenges, including any impact or outcomes, considering:

- **Key accomplishments achieved by NAAF include the following:**
  - **A decrease of emotional suffering and an increase in self-confidence.**
    - This was measured by the patient partner feedback on the evaluation forms from the support session.
    - There were twenty five support sessions in addition to the General Sessions. Support sessions covered topics such as relationships and intimacy, “It’s okay to feel sad”, Elementary school boy, elementary school girl, etc. The average rating of all support sessions was 1.2 (1 being excellent- 4 being poor).
      - “Thank you to all who worked so hard over the years to research, plan and provide so much comfort to those of us who have been touched by alopecia. NAAF has made a big difference in how I have continued to cope and feel better about myself.”
  - **A growing interest in the HARA Program**
    - NAAF is recruiting patient stakeholders to become Health and Research Ambassadors. As previously mentioned, following Angela Rodgers presentation, All 12 people who were invited attended and 3 additional people who heard Ms. Rodgers talk joined at their own request. Interest in the program was very high with 13 of 15 expressing an interest in becoming Health and Research Ambassadors.
    - Based on our breakout luncheon discussion, the next steps for the HARA program include developing a referral list of mental health professionals who are experienced and well-versed in supporting people with alopecia areata, totalis, and universalis. This work builds upon Angela’s progress during the HARA pilot program to educate medical doctors and students about the importance of addressing mental health issues in patients with alopecia areata and being prepared to make referrals.
  - **A better understanding of the types of questions of the types of questions that need to be asked to our patient community in order to provide meaningful feedback into the system about outcomes that matter to people with alopecia areata.**
    - The HARA Breakout Session and the Alopecia Areata Market Survey revealed the need for dermatologists to have a better understanding of the mental health implications involved with alopecia areata and for them to be able to offer resources for support.
  - **Increased engagement from our stakeholders to raise awareness of alopecia areata. Increased understanding of the need and patient demand for safe and effective treatments.**
Alopecia Areata was chosen as one of 16 diseases out of 22,000 for and the Food and Drug Patient Focused Drug Development Initiative. We will be able to use the findings from the Alopecia Areata Market Survey to inform this meeting. One of our funders was made further aware of the emotional toll of Alopecia Areata and invited a proposal from NAAF to support our public awareness campaign.

- **Accomplishments achieved during the project, with reference to project and patient engagement activities as described in your original Project Workplan and Timeline document:**
  - 688 people attended the Conference, coming from 40 U.S. states and eight foreign nations. Of that total, 306 were “VIPs” - enjoying their first NAAF Conference. NAAF hosted General Sessions with informative presentations by experts in the field highlighting the latest in research and treatment options.
  - The Conference had several inspirational sessions seeking to empower attendees such a talk by NBA Player Charlie Villanueva and a “Reality Star Round Table” featuring reality television stars that live with alopecia areata.

- **Challenges that were faced (e.g., delays in IRB approval, completion of engagement focus groups, participant retention issues), and how you overcame these challenges and/or addressed them:**
  - This year we found ourselves challenged to identify sessions and activities that speak directly to the 18-33 year age group. There is a kid’s camp and a teen’s camp, and many sessions for all other ages. We also had a “Young Adult Panel”, however, we heard from this age group that they would like more activities specifically focused for them. We also heard that even though there were printed programs and signage, they found it difficult to find sessions of interest.
  - Therefore, next year, we are planning an array of empowerment sessions tailored to this age group including more on dating and relationships, mentoring younger alopecians, and we will have a conference app as most people of this age group use their smart phones for information.

- **How did engaging with patients and stakeholders help the planning or conduct of this project? Please give specific examples:**
  - Planning for the Annual Conference begins with our Stakeholder evaluation review and feedback. It is by hearing from our community about what is working for them and not that we are best able to address PCORI Engagement Awards Final Progress Report 14 their needs and deliver programs and information to them in a meaningful way. Our patient stakeholders are involved every step of the way. Patient Stakeholders lead support sessions at the Conference, provide feedback about the type of scientific information they want to hear at the General Session and what types of activities would be fun and engaging for children at the kid’s camps.
  - Our recent Conference review session revealed the need to move beyond sessions that only deal with the emotional aspects of living with alopecia areata and info empowerment by using role playing. Patient stakeholders also expressed how helpful it for her to meet other young woman living proudly with bald heads when she was a little
girl and is now in the process of working with NAAF to create a mentoring program for
the Conference.

Describe the plan to disseminate the results from the project. Include any potential facilitators and/or
barriers to dissemination. Describe potential for results to be incorporated into practice, if relevant:

- Results from the Alopecia Areata Market Study will be presented at the World Congress for Hair
  Proceedings from the Research Summit are published in the Journal of Investigative
  Dermatology.
- Results from the first year of the HARA Program will also be presented at the NAAF Research
  Summit in 2016.