IFAA 2014

2014 has been a building year for IFAA, as we recognized our need to grow in order to continue identifying and solving community problems. We restructured our business model while spending time revising our representative training program, all in preparation for the upcoming years, as patient-centered nonprofits are deemed the wave of the future.

Our major program focus was patient-centered research, as we spent the entire year working on our Early Symptoms of Autoimmune Arthritis patient-led investigation, in addition to World Autoimmune Arthritis Day, the Media Awareness Hotline, and legislative advocacy.

We look forward to what the future brings for truly patient-centered organizations, as we spent 2014 gearing up to be that go to organization!

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**Year in Review**

**Patient-Centeredness.** For the duration of 2014, IFAA CEO, Tiffany Westrich-Robertson, took on the 1st ever patient-led investigation into the Early Symptoms of Autoimmune Arthritis, which aims to address the following equation: Early Detection + Early Referrals + Early Diagnosis + Early Treatment = Better Chance for Remission. If a patient's disease is detected early, it leads to an earlier referral to a specialist, which then results in earlier diagnosis and treatment. Patients who are treated early in their disease have a far better chance of combating unnecessary damage and disability, and can elevate their chances of achieving remission. After taking several courses in qualitative and quantitative research, Tiffany teamed with Valerie Milne, IFAA’s in house Patient-Researcher, and personal mentor Floyd J. Fowler, Jr., senior research fellow at the Center for Survey Research. The investigation is analyzing patient-reported early symptoms (adult onset through 24 months) of those diagnosed with Rheumatoid Arthritis, Psoriatic Arthritis, Sjogren’s Syndrome, Systemic Lupus Erythematosus, Adult Onset Still’s Disease, & Ankylosing Spondylitis to determine real symptoms, overlap, and perform a cross-comparison to current publications to identify inconsistencies. The results will be used to establish more cohesive and complete early symptom disease models. Results will be available in 2015.

IFAA also recruited the Spondylitis Association of America, Lupus UK, International Still’s Disease Foundation, and Sjogren’s Syndrome Foundation to serve as expert reviewers in data collection for original symptoms used to add to the data collection models.

**The Global Network** is IFAA’s philosophy to unite resources from all over the world so those affected by autoimmune arthritis and extended diseases can find the information they need to best manage their diseases. Our primary focus is to team with other groups, nonprofits, and advocates in order to provide stronger programs and to promote better health management, as demonstrated above in the Early Symptoms of Autoimmune Arthritis investigation.

IFAA is a member of the NIAMS Coalition, National Coalition of Autoimmune Patient Groups, hosted by AARDA (American Autoimmune Related Diseases Association), American College of Rheumatology, California Coalition for Chronic Care (CCCC), Medicare Access for Patient
Prescriptions (MAPRx), Patients for Biologics Safety and Access (PBSA), & National Institute of Environmental Health Sciences Partners (NIEHS).

World Autoimmune Arthritis Day, May 20th in every time zone (47 continuous hours) was established by IFAA in 2012 & is the largest global resource for those affected by autoimmune arthritis diseases in history. Hosted online, this year’s event estimated over 50,000 visitors from 16 different countries & 22 nonprofits participated in sharing resources. The event is currently listed on over 2 dozen health calendars worldwide. It serves as our major program, combining the global network, awareness, wellness education, advocacy, support, & research into one major initiative.

Conference Attendance. Since IFAA is run almost entirely online, it is important that are team participates in conventions and conferences that we believe will allow us to make a difference in patient lives. Kelly Conway, Co-Founder, spoke at the eXL Pharma Patient Adherence Convention, in July our team participated as Founding Partners in the Interdisciplinary Autoimmune Summit, and we hosted a booth at the ACR Scientific Convention in November.

Wellness Support. In October 2014, IFAA launched a pilot program, called the IFAA Nutrition Support Group, for those affected by any of the Autoimmune Arthritis diseases who may be looking to lessen processed foods and sugar intake, both of which contribute considerably to inflammation. The pilot program was a huge success, so we are currently working on gaining funding to launch a full program in the future. This is not an elimination diet or an alternative to medical treatment; it is a group to help you make better choices in nutrition, through accountability and support from other patients and IFAA. In addition to healthy eating the program will provide education on the biology of our diseases and how medications and other therapies are beneficial.
Financials 2014

**Public Support & Revenue**

- Grants $48,000
- Merchandise $1,781
- General Donations to IFAA/Fundraisers/Public Speaking $4,437

**Total Public Support: $54,218 (50% increase from 2013)**

**Expenses**

- Programs: $46,500
- Continued Education, Conferences: $3,200
- Overhead/Personnel Expenses: $3,700

**Total Expenses: $53,400**

IFAA effectively utilized all funds, keeping our overhead and personnel expenses under 7%. We are able to do this with the help of our volunteers, who are trained for a period of three months and who are encouraged to utilize their skills and talents to help develop and run our programs. In addition to the “IFAA Representatives”, who donate on average 30 minutes a week to IFAA, “General Volunteers” (or those who help temporarily with a specific task or host a fundraiser) also play a key role in our success. Volunteers are 99% patients affected by Autoimmune Arthritis and related diseases. **This year our team**
accumulated over 8,000 hours of volunteer service. This organization includes but not limited to communicating internally and publicly, attending conferences, trainings and teaching others, and program development and management. Based on local wages for similar services, IFAA donated an additional $160,000 in financial support to our community.