IFAA, an International Foundation for Autoimmune & Autoinflammatory diseases with Arthritis as a major component, is an award-winning organization. IFAA works to eliminate the adversity associated with these diseases by using our role as patients to communicate with our community, which helps us to identify the most pressing issues. Then, using our educational and business backgrounds, in conjunction with collaborations with other nonprofits, advocates, companies, & various experts (“Global Network”), we develop & implement solutions. Our key focus areas are Awareness, Education, Research, and Advocacy.

Focusing on the group diseases that are both similar in autoimmune and autoinflammatory features, in addition to their inflammatory arthritis components, enables us to work towards expediting detection, diagnosis, and treatments - which is necessary to prevent unnecessary disability.
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A Year in Review

Dear Supporters,

2017 has been an outstanding year for IFAA, thanks largely to our collaborations with fellow patients and other organizations. It is also partly due to five years working towards developing our original nonprofit model, in which we use our position as patients to identify the most pressing community issues, then use our backgrounds in business, education and research - as well as our collaborations with other nonprofits, advocates, companies, and experts - to implement solutions. While this unique structure has earned us accolades from many companies and fellow nonprofits, as when anything is ‘new’, the concept hasn’t been as easy to understand for the general public who only identify with the way nonprofits normally are designed. As we move forward in 2018, we hope to focus on making the “what we do” clear!

For those who have been supporters, we thank you tremendously, especially for believing in us when others doubted this model could work. For those newly introduced to IFAA, we look forward to getting to know you, and more specifically, what issues are important for you to see solved. Lastly, if you are a patient, whether you’ve been with us for years or it’s your first day - you are the heart and soul and THE VOICE in all we do. As I always say, “Together we can move mountains. Bulldozers are so overrated.” Plan on moving some mountains, IFAA has hit our stride!

_Tiffany Westrich-Robertson_
Chief Executive Officer
IFAA
International Foundation for Autoimmune & Autoinflammatory Arthritis
Why IFAA?

There are already nonprofits that focus on arthritis, those that advocate for all autoimmune and autoinflammatory diseases, and those that are disease-specific. Most have awareness and education programs, support research for a cure, and advocate for public policy issues that affect the patient population. So why IFAA?

- **Need for this disease focus.** There are well over 100 diseases that are autoimmune and/or autoinflammatory, and these diseases often present with symptoms that include fatigue, fevers, brain fog, tissue pain, and a general feeling of being unwell. However, only a couple dozen of those autoimmune/autoinflammatory diseases also include inflammatory induced arthritis as a major disease component. By bringing focus to this specific subset of diseases, including what is similar and different among them, we will help to expedite early detection, referrals, diagnosis, and proper treatments.

- **Increase awareness and understanding** about symptoms, disease impact on relationships and lifestyle, the genetic + environmental influences responsible for triggering these diseases, and the serious complications that can arise when not managed early and effectively.

- **Expedited detection, referrals, diagnosis, and best therapies.** Too many patients wait months, even years, before they are referred to a rheumatologist or other specialist trained to diagnose them. Even then, these disease can take time to develop symptoms characteristic of just one disease, making diagnosis difficult. Furthermore, some patients overlap in diseases, develop dual diagnoses and/or comorbidities - which get more complicated to treat the longer they go without proper therapy. Advanced education will expedite the path to better disease management and lessened potential disability, resulting in lower healthcare costs and a better quality of life for those affected.

**Research that focuses on the individual patient, rather than based on clinical trials that only test efficacy in patients who fit a 'typical' patient profile.** Since most patients with these diseases are unique in presentation and disease progression, and many have multiple, overlapping diagnoses and/or comorbidities, research must start to focus on the 'atypical' patient. Current treatments that may not work for an 'atypical' patient, including those with dual diagnoses or comorbidities, contribute to higher costs to patients who may fail many treatments
before finding the one that works best, and to both the patient and healthcare system long term if the result of delay in proper treatment is disease complications and/or disability.

Our combined experiences - business professionals, former and current educators, participation in patient-centered research efforts, and as patients ourselves - makes IFAA unique. Add that to our proven track record to unite global resources, success in managing large scale projects, and outstanding track record to produce outcomes that are important to our community - then you know why we need IFAA!
The Machine Behind the Scene

At IFAA we are patients. Not only do we manage IFAA by using our backgrounds as educators and business professionals, but we belong to the community we serve. From our CEO and Co-Founders to Executive Assistant, Training Coordinator, and Representatives, we are all affected by these diseases. However, the issues we tackle at IFAA are complex, and often projects that are innovative and never before been attempted. So while we rely on our relationships with patients to identify the problems, and our own professional experiences to develop solutions, we also reach out to other advisors/consultants and nonprofit partners to ensure we have most well-rounded team of experts to create the best outcomes. At IFAA, the patient voice will always be #1.

All projects begin by listening to the community and by living each day as patients ourselves. Once a problem or a gap in a current process is identified, IFAA engages our internal team of Representatives to brainstorm about solutions in our Virtual IFAA Representative Center. From there we determine the scope and external staff/consultants necessary to complete the project and work towards funding the initiative.

The IFAA way is the patient way – we know what the community needs and we work tirelessly to make sure it happens.
**Headquarters.** While IFAA primarily runs through virtual officing - to accommodate patient employees and volunteers who require flexibility in scheduling to achieve optimum performance, our headquarters office is part of a co-working space in downtown St. Louis, MO. This enables us to use conference rooms & event spaces as needed. The space is national, so we also have access to offices in all participating cities.

Patients are at the core of all brainstorming, program development, and project implementation. In addition to continuous engagement and assessment of the patient population, we have two levels of volunteers who are key participants and partners.
The Global Network

IFAA strongly believes in teaming with other organizations in order to achieve the best results in regards to community issues those affected by these diseases face.

Our Global Network philosophy embraces community unity and encourages organizations, advocacy groups, and other resources around the world to work together to develop the best programs and implement high-quality solutions that will best benefit the patient community. We strive to work together rather than to compete, so utilizing the "global network" is an essential component in everything we do.

- **Subcontractors** are hired as needed, which keeps our core team small & ensures we get the 'best of the best' assistance for each unique project (or when we are running dual projects at the same time).
- **Advisors** are utilized from both skill specific and from the medical community. Sometimes they volunteer their services, other times they are paid an honorarium for their contributions. Advisors are selected for each initiative, rather than enlisted one Advisory Board to oversee every internal need.
- In addition to contracting professional assistance and advisors, we collaborate with other nonprofit organizations and/or Patient Advocates on every project we do. We simply believe that together we can make the biggest difference.
2017 Global Network Collaborations

Subcontractors, Partners, Advisors, & Patient Advocates

A Community Team (ACT)

- Carol Cosenza, MSW - Advisor & Subcontractor
  Research Fellow, Clinic for Survey Research-Boston MA
  Advisor & review assistance for focus group/Hub design & formulating research questions for qualitative and quantitative initiatives, IRB submission.

- Sharon L. Newbill, Ph.D - Subcontractor
  Qualitative Research Expert, University of New Mexico Professor, Folkstone Evaluation Anthropology Research Services
  Lead, qualitative analysis, worked with Patient Research Liaison to form qualitative research review team/partnership (Patient - Research Partnership)

- National Databank for Rheumatic Diseases (NDB) - Advisor
  Researcher Recruitment, Survey Review

In addition to IFAA staff and volunteers (all patients), the following Patient Advocates were contracted to help with recruitment, focus group moderating, and patient-led researcher interviews.

- Julie Cerrone, Psoriatic Arthritis (PsA) Patient, Blogger - It’s Just a Bad Day, Not a Bad Life; 2014 Stanford Medicine X ePatient Scholar
- Charis Hill, Ankylosing Spondylitis (AS) Patient, Blogger - Being Charis: A Voice for Many; Sacramento area Spondylitis Association of America Educational Support Group
- Marel Pike, Psoriatic Arthritis (PsA) Patient, Online Support Group Administrator - Secret Psoriatic Arthritis Business

Biosimilars Educational Video Project

- ProPatient
- Med-IQ

Ethics of Step Therapy Investigation - Using the Paper for Public Policy Efforts

- Kathleen Arntsen
**Organizations** we work with not only during World Autoimmune/Autoinflammatory Arthritis Day, but often throughout the year in many ways - including sharing of projects, public policy efforts, and coalition work. These groups included:

| AMERICAN AUTOIMMUNE RELATED DISEASES ASSOCIATION (AARDA) | INTERNATIONAL PAIN FOUNDATION |
| AMERICAN BEHCET’S DISEASE ASSOCIATION | INTERNATIONAL STILL’S DISEASE FOUNDATION |
| AMERICAN COLLEGE OF RHEUMATOLOGY | JOINTHEALTH/ARTHITIS CONSUMER EXPERTS |
| ANKYLOSING SPONDYLITIS INTERNATIONAL FEDERATION | LUPUS AND ALLIED DISEASES ASSOCIATION (LADA) |
| ARTHRITIS FOUNDATION | LUPUS UK |
| ARTHRITIS NATIONAL RESEARCH FOUNDATION | NATIONAL ANKYLOSING SPONDYLITIS SOCIETY |
| ARTHRITIS NEW ZEALAND | NATIONAL DATABANK FOR RHEUMATIC DISEASES |
| CANADIAN SPONDYLITIS ASSOCIATION | NATIONAL INSTITUTE OF ARTHRITIS AND MUSCULOSKELETAL AND SKIN DISEASES (NIAMS) |
| COORDINADORA ESPAÑOLA DE ASOCIACIONES DE ESPONDILOARTRITIS (CEADE) | NATIONAL ORGANIZATION FOR RARE DISEASES (NORD) |
| CREAKY JOINTS/GLOBAL HEALTHY LIVING FOUNDATION | NATIONAL PSORIASIS FOUNDATION |
|  | NATIONAL RHEUMATOID ARTHRITIS SOCIETY |
**Coalitions.** In order to overcome obstacles for our community, nonprofits often unite under “Coalitions”. Some of the Coalitions IFAA participates in are to advance research. These types of united efforts aim to establish guidelines and expand innovation. Several are associated with advocacy efforts. To advance policy to ensure protections and access to proper treatments, nonprofits unite to represent the patient voice to a maximum level. While all nonprofits also have their own internal programs and impact, when change to regulatory practices, research guidelines, or policy is at stake, it takes collaboration to move the needle.

**We are proud members of the following coalitions:**

**Friends of National Institute of Dental and Craniofacial Research (FNIDCR), Section member of the American Association for Dental Research (AADR)**

This coalition unites nonprofits who advocate for special needs in dental care and research.

**Patients for Biologics Safety and Access (PBSA)**

The PBSF is a national coalition representing more than 20 patient advocacy organizations working to ensure that the voices and interests of patients are heard as the FDA considers approval of a new category of drugs known as biosimilars.
The National Coalition of Autoimmune Patient Groups (NCAPG)
Hosted by AARDA (American Autoimmune Related Diseases Association). Mission: To consolidate the voice of autoimmune disease patients and to promote increased education, awareness, and research into all aspects of autoimmune diseases through a collaborative approach.

NIAMS Coalition (National Institute of Arthritis and Musculoskeletal and Skin Diseases)
Two of IFAA's Founders, Tiffany Westrich & Tami Brown, are honored to serve on the NIAMS Coalition. The Coalition is a group of professional and voluntary organizations concerned with the programs of the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS).

California Coalition for Chronic Care
The CCCC is a unique alliance of more than 30 leading consumer health organizations and provider groups that promote the collaborative work of policy makers, industry leaders, providers, and consumers to improve the health of those with chronic conditions.

Nevada Partnership for Access to Treatment
Partnership to help elevate awareness of Nevadans living with chronic conditions and advocate on behalf of patient access to care and treatment.

Medicare Access for Patient Prescriptions (MAPRx)
MAPRx is a coalition of patient, family caregiver, and health professional organizations committed to safeguarding the wellbeing of patients with chronic diseases and disabilities who rely on Medicare Prescription Drug Coverage.

Protect Medicare Part D Working Group
aims to keep our organizations updated on policy developments that could impact patients’ access to medications through Medicare. These working group calls provide a forum for organizations dedicated to patient health to share resources and ideas for advocacy.

National Institute of Environmental Health Sciences Partners (NIEHS)
Working with the Partners allows the NIEHS to learn more about the priorities of these organizations, and helps to shape the institute’s research agenda. In turn, these organizations learn about the NIEHS research enterprise and about the other partner organizations.

Partnership to Fight Chronic Disease
Chronic disease is not only the number one driver of health care spending, it presents a significant human and economic threat.

Patient Access for Florida
Ultimately, healthcare professionals, not bureaucrats, should make the determination of the best course of treatment and medications for a patient. We need to ensure Florida's patients are receiving the right medicine at the right time.
Healthcare Leaders for Accountable Innovation in Medicare (AIM)
Leading voices from across the healthcare spectrum have a shared belief that Medicare should be more quality-driven, cost-efficient, and patient-focused.

Part B Access for Seniors and Physicians (ASP) Coalition

World Arthritis Day Ambassador
While IFAA hosts World Autoimmune Arthritis Day, we also help EULAR, organizers of World Arthritis Day, to raise awareness about the day and coinciding awareness events surrounding the day.
Projects & Accomplishments

IFAA’s work focuses on the specific group of patients living with autoimmune or autoinflammatory diseases with arthritis as a major component. These diseases are highly similar in onset causes, disease symptoms, progression, comorbidities, and treatments. We believe by focusing on this subset of diseases that we can help to expand awareness, education, research, and access to care for this population (advocacy). All of our projects, collaborations, and public policy work center around this core mission.

2017 Project Work

Advocacy (General)

In 2017, IFAA joined two advisory panel groups - led by the US Arthritis Foundation and National Psoriasis Foundation - to discuss obstacles in step therapy and non-medical switching (when patients are forced off medications chosen by their doctors for financial reasons instead of considering medical rationale) - and four additional coalitions that work towards protecting patient access to proper and necessary treatments. Throughout 2017, IFAA participated in several calls per month with various coalition groups, and was in Washington D.C. on a half a dozen occasions to speak on behalf of patient issues.

IFAA was also very active in a coalition we joined in 2015, the Patients for Biologic Safety and Access (PBSA), as the first biosimilar agents to be approved on market in the US (biosimilars are treatments that are similar, but not exactly the same, as existing treatments called biologics). They were approved in Europe prior to 2015, so IFAA is also working with other nonprofit groups internationally to stay abreast of news regarding their safety and efficacy reporting.
**Education: Biosimilars**

In addition for advocating for biologic and biosimilar safety, IFAA teamed with Med-IQ and ProPatient to design short educational Q & A videos that help patients better understand biosimilars and what their introduction to market means to disease management. Tiffany Westrich-Robertson, IFAA’s CEO, a patient and former college professor, helped write the script and hosted sections of the videos. *Note: The grant was for Rheumatoid Arthritis specific education, however, the information in the videos is relevant for any patient who may be prescribed biosimilars.*  

View videos

**Advocacy, Education, Research: Ethics of Step Therapy**

In June 2016, IFAA joined other policy experts from the Arthritis Foundation, Applied Pharmacy Solutions, and Assemblymember Adrin Nazarian (California) to lead a panel for health care providers and patients which explored how step therapy policies keep beneficiaries from getting medications their doctors prescribe and add barriers to patient access to care. IFAA specifically discussed the ethics of step therapy investigation (led in 2015), which demonstrates how payers cite research to justify cost. Since both payers (insurance companies in the US, for example) and providers (doctors) have an ethical responsibility to treat based on cost control and proven research, the payers base their decisions on what works best for the “general patient population”. Where this can harm our patient population is when the patient who does not meet the standards for “general patient population”, due to atypical onset or comorbidities for example, are forced to use the same treatments.

Therefore, in addition to using the findings from this investigation for public policy purposes, IFAA is also using it as the backbone to an award-winning research project we began in 2016 - A Community Team (ACT). [View the Ethics of Step Therapy Investigation](#)
Research: A Community Team (ACT)

A large percentage of 2016 was spent on ACT, one of three innovation in research grant winners – and the only immunology winner - in Celgene’s Innovation Impact Awards, November 2015. In a time when “patient-centered research” is at an all time high, IFAA wanted to push the boundaries to test just how far we could get the patient voice involved…and boy did we!

The concept of ACT was to test various collaboration platforms between patients, researchers, and industry to improve treatment outcomes and better use research dollars. The initial planning project, which launched in early 2016, focused on understanding patient treatment decision drivers and studying existing R & D processes which included:

- Investigating current researcher & industry-reported barriers and benefits to patient research participation.
- Testing various communication platforms that could elevate patient engagement in the research process.
- Including a larger, more inclusive sample of patients – instead of only including the typical patient advocate – and evaluated the value of patient leadership as part of the research team.
- Investigate potential pros and cons of using patient leaders in Research & Development phases of a project, with expert advisors in place to help with the design and authenticity of the research.

By the end of 2016, the project successfully:
- Completed development of a ‘Hub’, which included functional methods to engage a larger and more inclusive patient population as a voice in research.
- Pushed innovative tactics by flipping typical practices of Patient Research Partnerships (PRP), where patients act as advisors on research projects.
- Tested a "Patient Initiated Research" platform that may justify future cost savings strategies associated with putting the patient in leadership roles.
- Conducted 22 patient led interviews over 2 days with both researchers and nonprofit leaders who currently engage in patient-centered research at some capacity so we could expand on already recorded benefits and barriers and begin the discussions how to expand engagement.

In February 2017 IFAA hosted an online, interactive "virtual roundtable" inclusive of those around the world who are identified as active in various levels of patient centered research. Invitees will range from researchers (pharmaceutical and non pharmaceutical researchers), Clinical Research Organizations (CRO's), Industry Representatives, Nonprofits/Coalitions, and Patients who were leaders on the first two phases of the ACT project. Attendees were asked to participate in live polls and discussions current accepted Patient Engagement methods and were encouraged to think of ways to expand engagement moving forward into ACT II.

Learn more about the ACT Project, including plans for ACT II in 2017

**Awareness, Education: World Autoimmune/Autoinflammatory Arthritis Day 2017**

World AUTOimmune and AUTOinflammatory Arthritis Day is an online, annual awareness event designed to mimic an actual car race, complete with live breaking news, rallies (awareness posts), and over two dozen Nonprofit "Race Teams" competing to see who can raise the most awareness during the event. This 47 hour event, which is the duration of May 20th throughout all time zones globally, is a one-of-a-kind, exciting way to educate the world about our diseases.
This event provides patients from anywhere in the world, regardless of physical limitations, the

#WAAD17 is an online awareness “virtual race” held on May 20th in all time zones globally. Learn more www.WAAD17.org
ability to find 100’s of resources for disease management, as well as the opportunity to interact with other community leaders just by logging into the internet.

WAAD16 engaged over 100,000 people, with three dozen Official Nonprofit Race Teams and four umbrella organizations (ACR, EULAR, NIAMS, and WEGO Health) who participated as Resource Kiosks. Participants were recorded from 57 countries, with the United States representing the majority.

Thank you to those organizations who supported the event! And congratulations to the winners:

You can learn more about World Autoimmune/Autoinflammatory Arthritis Day here
"Team" is the key word when thinking about how IFAA works and why we are recognized for our exceptional contributions to the autoimmune, autoinflammatory, and arthritis communities. In 2012, our first full year as an organization, we won "Best Ensemble Cast" for our work in the awareness and wellness education arena. Since then our nonprofit and active representatives have collectively been nominated for over 3 dozen awards since inception. Our passion and commitment to making a difference is evident in all we do.

In the last five years we have been nominated for WEGO Health Care Awards- Best in Show: Community all five years, plus collectively our IFAA founders and Representatives have been nominated for over 2 dozen awards, including individual nods for Healthcare Hero. Teamwork and community are both in the heart of all we do. We are proud our efforts have not gone unnoticed!
Financials

2017 Annual Report Revenue and Expenses

We thank our supporters for your contributions, which enable us to continue creating, developing, and implementing solutions to problems most important to our community. We rely heavily on support from public donations, project grants, and in kind services to successfully complete the necessary work we do for our community. Again, thank you to all who supported IFAA in 2017!

PUBLIC SUPPORT AND REVENUE

Public Contributions $4,850
Program Grants $58,000
Merchandise $475
Unrestricted MIssion Support $25,338
Volunteer Contributions* $107,045

Total Cash Revenue $88,663
Total In-kind Revenue * $107,045

TOTAL REVENUE $193,366

EXPENSES

Program Expense $48,000
Conferences $5,551
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<td>Subtotal In-kind Expense</td>
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</tbody>
</table>

**TOTAL EXPENSE**  
$193,366

**REVENUE OVER EXPENSE**  
$2,341

*The International Foundation for Autoimmune & Autoinflammatory Arthritis relies heavily on donated manpower hours to achieve our mission and provide our program services. In 2017, 17 volunteers, including our CEO and all co-founders, accumulated over 5,000 hours of volunteer-contributed services. Based on the Independent Sector’s State Values of Volunteer Time Missouri 2017 rate of $21.57 per hour, IFAA raised an additional $107,045 in financial support, making our total annual revenue $193,366.*