"2020 was a year of unprecedented circumstances, and as a result, the world united in a way I’ve never seen before. Initial fear, confusion, and uncertainty taunted our community, but in time, acceptance, clarity, and confidence began to emerge. We, alongside many other organizations in the rheumatology community, worked tirelessly to ensure people with AiArthritis diseases had the resources needed to navigate through these uncharted times. Through the darkness we prevailed, thanks largely to the supporters who believed in our work. To you we say, ‘Thank you!’"

- Tiffany Westrich-Robertson, Chief Executive Officer
Dear Supporters,

I usually start this letter with a celebratory statement, looking back on successes based on what we have built over the last nine years as an organization. But in 2020, we could not have been prepared for the unimaginable circumstances that impacted all lives to the core. Whether a person with AiArthritis diseases, or not, for the first time all persons were experiencing a glimpse into our world - a world where we must worry about protecting our immune systems and where we are forced to stay home when we would rather be with friends and family. The world experienced a ‘new normal’, but for us, it was just our normal. For our organization - which as always conducted business online and virtually - other groups flocked to us for advice, which we were happy to provide.

In our patient community, chaos and constant mixed messages plaguing our online groups was at an all-time high, so AiArthritis vowed - as persons living with AiArthritis diseases ourselves - to jump into the trenches and serve as both information liaisons and trusted advisors not only in our organization-led groups, but for any AiArthritis disease support group who needed assistance combatting the misinformation.

COVID-19 also highlighted the inequities of our healthcare systems; “diversity” and “access for all” became a staple of conversation. Yet this is something AiArthritis has been working towards for years, put into action in 2015 with the award-winning innovation in research project - A Community Team (ACT), from which the ACTION Council project and the new AiArthritis Voices online community and related AiArthritis Voices 360 Talk Show all emerged. In an unexpected way, COVID-19 helped bring attention to the work we have been doing all along to bring all voices to the table - regardless of geography, disease limitations, or prior advocacy experience.
COVID-19 also shined a light on other work we had been doing already, like working to improve shared decision-making, which we tackled in our Talk Show series spin-off, *RheumyRounds*, in our *Preparing Patients for Precision Medicine* project, and as members of the *OMERACT (Outcomes in Rheumatology) Shared-Decision Making Working Group*. Advisory panels that once required patient participation in person all moved virtual, opening the door of opportunity for us to connect persons with AiArthritis diseases to be the voice in a way never before possible (because these people are not able to travel). Conferences moved virtual, too, so we established a new program, *“Go with Us!” to Conferences*, inviting patients interested in research to join our team as we help them navigate and learn from sessions at the American College of Rheumatology (ACR) and European League Against Rheumatism (EULAR) annual meetings.

On a personal note, as a person living with non-radiographic axial spondylitis, I was proud to lead AiArthritis in the fight to secure an official disease code by organizing a large online “*Code4nrAxSpA*” campaign and writing several heartfelt letters to the *National Center for Health Statistics* throughout 2019. This past summer we were notified there was a new code and, in saying this, my disease is officially recognized!

**Tiffany Westrich-Robertson**  
*Chief Executive Officer*  

*International Foundation for Autoimmune & Autoinflammatory Arthritis (AiArthritis)*
Mission: We are led by people affected by AiArthritis diseases who use this lived experience to connect with a global pool of patients and then use our professional backgrounds to connect those patients with other stakeholders, so together - as equals - we can solve problems that will impact education, advocacy, and/or research.

We expand this mission into every project we work on. We always use a patient-led team approach, then enlist the help of other stakeholders and professionals, to produce strong solutions with high impact. (“Global Network philosophy”).

We are problem solvers. As people living with these diseases ourselves, with the help of support staff and many volunteers, we identify issues of unmet need and then work alongside other stakeholders - AS EQUALS - to work out solutions. Some of our initiatives can be done in a year, others take several years ... but the result is always meaningful with high impact!
**Mission Work**

Our work is divided into mission work, or initiatives that support our everyday purposes for solving problems that impact education, advocacy, and research.

On a daily basis, our organization works to help make sure we all have the best lives possible while living with our diseases. So we are continuously putting effort towards

- Earlier detection and diagnosis
- Access to the best treatment at the right time - and based on the individual characteristics of the patient
- Supporting research
- Improving communication, education, and awareness

AiArthritis Voices is still in progress, but when it launches in 2021, watch out! This is just one part of the work we are doing to build on results from our award-winning A Community Team (ACT) project (2015) - where we began developing novel and diverse methods of communication to bring all voices to the table. Aimed to launch fully in the summer of 2021, this initiative will become our mission in action. Patients and all other stakeholders (family members, doctors, researchers, pharmaceutical companies, etc.) can sign up to be connected with opportunities to help us solve the problems that matter most to our community. Learn more.

It's so much more than a ‘podcast’, the award-winning concept aims to elevate what we do within the AiArthritis Voices program to next levels by incorporating an unlimited number of communication methods to ensure we reach all voices. From live watch parties to traditional audio recordings to one-day, in-person events, the goal of this Talk Show is to find the people who need to be at the table and invite them to it. And if not during the show, then pull up a seat afterwards!

The first year as a Talk Show, we were nominated for Best Podcast (WEGO Health), and starting in December 2020, we have been the top ranked arthritis show on Feedspot.
Advocacy

Our priorities, in addition to anything COVID-19 and preparing for vaccines, we are now part of two dozen coalitions, 75% of which are public policy related. We have been focusing on anything that involves access to therapy, accumulator, nonmedical switching, pricing index, and transparency.

Thank you to Pfizer, PhRMA CA, and PhRMA NV for providing grant support to enhance our advocacy efforts in 2020.

New Coalitions in 2020

In 2020, we were the only US-based nonprofit invited to be a part of the Global RA Network. Founded in 2016 by Rheumatoid Arthritis (RA) patient organizations and leaders from 18 countries, the Global RA Network was formed to build international relationships and identify and work on common goals and initiatives to improve the lives of people living with RA around the world. Arthritis Consumer Experts (Canada) serves as the Network’s secretariat. AiArthritis is the only organization representing the United States of America.

https://globalranetwork.org/

Clinical Trials Transformation Initiative (CTTI): Their mission is to develop and drive adoption of practices that will increase the quality and efficiency of clinical trials. They evaluate clinical trial issues and help find solutions. https://www.ctti-clinicaltrials.org/

COVID-19 Advocacy Exchange: A virtual platform to unite advocacy organizations, patients and industry in the exchange of information.
https://www.covidadvocacyexchange.com/

COVID-19 Vaccine Education and Equity Project: Provides education on, and advocates for adherence to a gold-standard regulatory review process, to raise awareness around the importance of COVID-19 vaccination for public health, the economy and broader society, promote the impact of widespread vaccination, and help ensure equitable access.
https://covidvaccineproject.org
Other Coalitions:

International

**Global Genes RARE Foundation Alliance:** Comprised of over 450 disease foundations that have committed to collaborating with Global Genes and other nonprofit foundations in order to create a stronger, collective voice in the rare disease community. [https://globalgenes.org/foundation-alliance-2/](https://globalgenes.org/foundation-alliance-2/)

**International Alliance of Patients' Organizations (IAPO):** A unique global alliance representing patients of all nations across all disease areas and promoting patient-centered healthcare across the world. [https://www.iapo.org.uk/](https://www.iapo.org.uk/)

**Personalized Medicine Coalition (PMC):** Representing innovators, scientists, patients, providers and payers, PMC promotes the understanding and adoption of personalized medicine concepts, services, and products to benefit patients and the health system. *AiArthritis is currently the only organization involved focusing on all of the diseases under the AiArthritis umbrella.* [http://personalizedmedicinecoalition.org/](http://personalizedmedicinecoalition.org/)

**Alliance for Safe Biologic Medicines (ASBM):** It is the mission of this Alliance to serve as an authoritative resource center for the public, medical community, the U.S. Food and Drug Administration and government regulators worldwide as biosimilars policies are developed and implemented. [https://safebiologics.org/ See our work on biosimilars education.](https://safebiologics.org/ See our work on biosimilars education.)

**World Patients Alliance (WPA):** The umbrella organization of patients and patients’ organizations around the globe that seeks to ensure that all patients have access to safe, high quality, and affordable healthcare everywhere in the world. [https://www.worldpatientsalliance.org/](https://www.worldpatientsalliance.org/)

US Based

**All Co-Pays Count Coalition:** Group led by the US Arthritis Foundation to address patient access to prescribed medicines due to insurance "accumulator" issues. *We are also members of and support several break-out, state-level All Co-Pays Count Coalitions.*

**Alliance for Transparent & Affordable Prescriptions (ATAP):** This group of stakeholders has united to address the rising costs of prescription drugs and patient access to affordable treatments by regulating Pharmacy Benefit Manager (PBMs) practices and reforming the drug industry through educational outreach and grassroots advocacy efforts on both federal and state levels. [https://atapadvocates.com/](https://atapadvocates.com/)
**Arizonans for Step Therapy Reform:** Focus is to reform step therapy laws in Arizona.

**Californians for Improved Patient Access:** A coalition of patients, providers, advocates, and lawmakers who are working to improve Californians’ access to needed healthcare.

**Californians for Stem Cell Research, Treatments & Cures:** Their initiative of 2020 will provide $5.5 billion to accelerate development of treatments and cures for life-threatening diseases and conditions that affect someone in nearly half of all families. https://caforcures.com/coalition/

**Friends of National Institute of Dental and Craniofacial Research (FNIDCR):** Section member of the American Association for Dental Research (AADR) and International Association of Dental Research (IADR). http://www.iadr.org/AADR/Governm ent-Affairs/Friends-NIDCR

**Healthcare Leaders for Accountable Innovation in Medicare (AIM):** Advocating for healthcare innovation that benefits patients, providers, and the American public. http://protectingmedicareaccess.com/

**Let My Doctors Decide (LMDD):** *Our organization holds an Advisory Task Force Chair on this US national partnership of leaders across health care working in support of curbing step therapy practices.* We believe treatment decisions should always be made by patients and trusted health care professionals, not insurance companies or pharmacy benefit managers. https://letmydoctorsdecide.org/about. *See the work we are doing in regards to Step Therapy: Ethics Investigation, ACT II, Preparing Patients for Precision Medicine.*

**Medicare Access for Patient Prescriptions (MAPRx):** MAPRx is a coalition of patient, family caregiver, and health professional organizations committed to safeguarding the well-being of patients with chronic diseases and disabilities who rely on Medicare Prescription Drug Coverage. https://maprx.info/

**The Part B Access for Seniors and Physicians (ASP):** Coalition is committed to ensuring continued access for this vulnerable population. http://www.partbaccess.org/
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. https://www.aarda.org/who-we-are/ncapg/

NIAMS Coalition: (National Institute of Arthritis and Musculoskeletal and Skin Diseases) Two of our Founders, Tiffany Westrich-Robertson & 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). https://www.niams.nih.gov/about/partnerships/niams-coalition

Partnership to Improve Patient-Centeredness (PIPC): Works to advance the principles of patient-centeredness in an evolving healthcare system by uniting a diverse, broad-based group of health care stakeholders who promote giving a voice to patients, giving choice to patients, and advancing value for patients. This group strongly works on advancing patient voices in value measurements. http://www.pipcpatients.org/

Safe Step Act Coalition: Led by the National Psoriasis Foundation, this is the prominent group in the US working to help legislative efforts surrounding step therapy. To view our organization’s work in step therapy, please view our Ethics of Step Therapy Project.

More Advocacy - Code for nr-AxSpA!

Starting in 2019, our organization joined forces with the Spondylitis Association of America and Rheumatology Nurses Society to push for an official disease code for non-radiographic axial spondyloarthritis (nr-axSpA), the diagnosis of our CEO, Tiffany Westrich-Robertson.

AiArthritis took the initiative to start a full-blown campaign on social media, tagging the Centers for Disease Control (CDC), in addition to writing several heartfelt letters, to press the importance of establishing this code. Without it, patients like Tiffany can have a more difficult time obtaining the treatments tested and proven beneficial for persons with earlier phase spondyloarthritis.
Additionally, we took to our AiArthritis Voices 360 Talk Show as another platform to voice the importance of patients having a name to their disease. *Episode #10, Patients Weigh In: Why the ‘Right’ Diagnosis Name Matters. Air date January 19th, 2020.*

In the summer of 2020, Tiffany received the phone call she had been waiting for - her disease, and the condition of thousands like her, was officially recognized with a code!

Education, Advocacy, and Research - a little of everything in the world of COVID-19

Thankfully, our organization has always been set up to run virtually, so in that respect COVID-19 did not hit us as hard as others. However, it did hit home in the rheumatology community, as not only were our patients on immunosuppressant drugs considered high risk for contracting the virus, but our medications were being tested to combat severe COVID. Everyone was looking for answers, but in the frenzy of it all - when even experts could only offer best guesses - organizations worldwide stepped up to help.

From February 2020 through April 2020, almost our entire focus became COVID-19. Projects were put on hold, and we put all our energy into developing a [COVID-19 & AiArthritis Special Series Talk Show](https://www.aiarthritis.org/blog Covid-19), a [COVID-19 resource page on our website](https://www.aiarthritis.org/blog Covid-19), and a [Facebook group dedicated to all things COVID-19](https://www.aiarthritis.org/blog Covid-19).

*Special thanks to Bristol Myers Squibb for their grant of $25,000 that helped make this a reality.*
**Project Updates**

Due to COVID-19 disrupting our schedule, all of our existing projects were put on hold until the end of December and, in some cases, will continue in 2021.

**World AUTOimmune & AUTOinflammatory Arthritis Day 2020**

In 2019, we told you that 2020 was the year we were moving entirely offline and putting ourselves out into the community. We planned for our first in person gala, the AUTO Ball, and the AiArthritis Voices 360 Talk Show was set to tour around the world. Then COVID-19 happened, and the AUTO Ball moved online via Facebook.

We recorded 12 videos, with guests including Suz Schrandt and Dr. Al Kim (shown above), Dr, Auralie Najm from OMERACT/EULAR, Dr. Lisa Zickhur from Washington University to talk about the importance of telehealth, Kaleb Michaud from FORWARD: National Data Bank for Rheumatic Diseases, and several of our recurring show patient Co-Hosts! (Deb, Danielle, Rick, Judy, Katie, Kelly, Estella, and Juana).

The theme was to compare our full body diseases to AUTOmobiles, with a special focus on the importance of differentiating arthritis types. The event reached 52 countries and was viewed by over 150,000. You can view all the videos here.

Thank you to Genentech for supporting this event at the $5,000 level.
September 7th, 2020 - Still's Disease Awareness Day

"I often find it difficult to talk about the effect this invisible illness has had on my life since my diagnosis a few years earlier, but I’m so glad to see more work being done to raise awareness for such a rare disease that’s had such a massive impact on me." - Katie

"Thank you for all of the stories. I now have a greater understanding of Still’s Disease. Health and wellness to all of you warriors!" - KM Smith

In 2017, the International Still’s Disease Foundation dissolved and asked AiArthritis to house all remaining resources - and gave us their blessing to try and take any education, awareness, and research efforts to the next level ... and we have.

In 2020, Still's Disease awareness day reached a huge milestone. In addition to general posts about Still's Disease, we worked with Health Unlimited to develop five videos, each featuring a person affected by Still's Disease in some way, and we launched the first ever patient-reported Still's Disease brochures. Additionally, we invited persons affected by Still's to submit their #MyStills stories, all in an attempt to raise awareness about the symptoms and realities of the disease, but also to showcase that it does not always present or evolve in patients the same. This leads to more complications in diagnosis and disease management.

The videos reached over 100,000 impressions and the brochures averaged 300 downloads per month over the three months tracked in 2020. The top twitter post reached 826,000.

- View all the #MyStills videos.
- View and download the brochures and medical cards.
- View full report.

Thank you Swedit Orphan Biovitrum (Sobi) for your grants in the amount of $10,000 for the brochures and $10,000 for Still's Disease Awareness Day that made this possible.
Every year our organization attends two of the most important scientific conferences - the American College of Rheumatology (ACR) and the European League Against Rheumatism (EULAR). Since our mission is to help other patients have a voice, too, alongside other stakeholders as equals so, together, we can solve problems impacting education, advocacy, and research, we decided to open up the conference experience to others as well.

The "Go with Us! to Conferences" pilot program was developed this past year, and we will continue to test different methods of interaction through 2021 (with the goal to fully launch in 2022). "We have been attending scientific conferences for a decade now," explains CEO Tiffany Westrich-Robertson, who is also living with axial spondyloarthritis. "These meetings are different because they are geared towards educating health care professionals, so the content is often complex and can be difficult for most patients to comprehend. Between our long-term attendance, internal work at patient-research partners and clinical trial grant reviewers, and professional backgrounds as educators, we felt we are in a position to connect other patients to this experience."

"We experimented with several methods of involvement, including private online chats, webinars, and live research review parties. We also spent weeks recording dozens of patient-led debriefs, focusing on the sessions we attended we felt would be of most interest to our community.”

One of the most successful methods of interaction was the private watch party for the Bristol Myers Squibb session on precision medicine. Attendees joined Tiffany, Deb, and Patrice as Tiffany walked through portions of the presentation, stopping intermittently to allow for questions and clarifying conversation. This also was conducted in conjunction with our Preparing Patients for Precision Medicine in Clinical Trials project, which requires education before we move into developing the shared-decision making tool that will help patients talk to their doctors more about trial participation.

All the debrief videos from EULAR 2020 can be found here. All the debrief videos from ACR 2020 can be found here.

In this case, to scientific conferences...

“This is absolutely the best resource for research I’ve seen in our community. The amount of information I’ve learned, not only about current research but also about my own disease journey and needs, is indescribable. Thank you, AiArthritis, for giving me and others this experience to ‘go with you’!” - Becky
Other Updates

Advisory Panels

- We nominated Deb Constien, one of our top volunteers, to serve as a Department of Defense grant reviewer (arthritis) under the AiArthritis name, and she was accepted. She spent most of 2020 participating in online reviews as the patient voice.

- Tiffany Westrich-Robertson (CEO) was invited to be part of Bristol Myers Squibb's PEER Panel of expert patient advisors.

- Tiffany was also selected to serve on the Missouri State Design Thinking Advisory Board, teaching other executives globally how to think differently and creatively in a methodical process (the same that we incorporate into all we do at AiArthritis - see our 6 step process that is based on Design Thinking). While not specific to our organization projects, it's still relevant to our work!

- Tiffany, who has already been a member of the Shared-Decision Making working group since 2019, was joined by dozens of other patients - including several of our volunteers and Talk Show co-hosts - for the historic voting to approve the SDM recommendations for clinical trial inclusion in rheumatology. (See photo below).
• **OMERACT (Outcome Measures in Rheumatology) Working Groups:**
  Before COVID-19, OMERACT had already decided they were going to try to bring more stakeholders to the table by opening activities to online participation. The pilot quickly turned to action in 2020, and AiArthritis - who already has staff and volunteers participating in working groups as patient research partners - stepped up to help. We recommended dozens of patients globally, who received invitations to get involved.

• Deb and Tiffany also participate in the following groups: Equity, Remission in RA - patient perspective, Contextual Factors, and Synovial Tissue in RCTs. Tiffany is also a main patient research partner for the Patient Outcomes in Longitudinal Studies (POLOS) working group.

**Thank you to our Team**

While we have always based our organizational foundation on virtual, flexible participation (to accommodate for patient flares), this was the first year we did not travel to conferences or meetings. Zoom and other online collaboration is not new to us, but as all people, we do miss the in-person interactions!

Thank you to our internal team of staff and subcontractors, as well as our volunteers who are the heart and soul of all we do.

While we stopped recruiting for more volunteers in 2019 - 2020 when our focus turned to building up the programs and platforms for 2021, we still had over a dozen people who never stopped supporting us and the work we do.
Our Impact Committee members are hand-selected, invited annually, based on demonstrated efforts to strengthen the voices of those affected by our diseases and their willingness to collaborate to advance our organization's mission and programs. Since our mission involves connecting people living with AiArthritis diseases with other stakeholders - as equals in problem solving efforts - we include a variety of stakeholders in our committee. We are thankful for our Impact Committee members, whose support is priceless!
Financials

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.

Public Support, Revenue, and Expenses

<table>
<thead>
<tr>
<th>Description</th>
<th>Amount</th>
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<tbody>
<tr>
<td>Public Contributions</td>
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<td>Program Grants</td>
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<td>Unrestricted Mission Support</td>
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<td>Volunteer Contributions*</td>
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<tr>
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<tr>
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<td><strong>Total 2019 Expense:</strong></td>
<td><strong>$207,250</strong></td>
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</table>

**Revenue Over Expense:** **$89,227**

*The International Foundation for Autoimmune & Autoinflammatory Arthritis relies heavily on donated manpower hours to achieve our mission and provide our program services. In 2020, 16 volunteers, including our accumulated over 1,500 hours of volunteer-contributed services. Based on the Independent Sector’s State Values of Volunteer Time Missouri 2020 rate of $25 per hour we raised an additional $66,275 in financial support, making our total annual revenue $296,477.

** 80% of all staff and 100% of subcontractor fees are directly associated with our programs. Our staff, also people living with AiArthritis diseases, serve as project managers and project assistants on all initiatives.