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Letter from our CEO & Founders

The International Autoimmune Arthritis Movement (IAAM) was founded due to an overwhelming need to bring awareness to a handful of diseases that have been, until now, lumped under the “arthritis” umbrella.

From advertisements to general conversation, differentiating and clarifying the differences between diseases that involve not only joint pain (defined as “arthritis”) with those that are much more complex has been almost non-existent. The result is a general public who believes that whatever strand of “arthritis” you have must be similar to the kind that can be fixed with an easy remedy, such as over-the-counter medication or simple dietary changes. It is even confused with causes traditionally related to Osteoarthritis, or joint pain resulting from wear and tear on the weight bearing joints.

The term Autoimmune Arthritis was coined by IAAM in 2009 in order to create an updated, politically correct way to address this group of serious, dangerous and in some cases, life threatening diseases. It is imperative that the public understand the severity of these diseases that can affect not only joints but also the soft and connective tissues, muscles and sometimes organs. They need to view them as systemic (full body) and acknowledge that they are often paired with obnoxious fatigue, fevers and nausea. It is time we classified the Autoimmune Arthritis diseases differently so that society can finally understand these diseases for what they are and work towards a better life for those effected. With understanding how these patients truly suffer those funding research can become more aware of the need to find a cure.

This is our first Annual Report, for IAAM was only granted 501c3 status in May of 2011, but we can assure you it is the beginning of a new world order of change, a time for better understanding and the launch of a platform where the world of Autoimmune Arthritis can come together to make a significant difference.

In this report you will learn about our current and future initiatives as well as the “machine behind the scene”, or the team that makes all of this possible.

2011 will forever go down in history as the year an official nonprofit was created to shed light on a handful of diseases that, until now, often took the backseat to the more common, popularized “arthritis”. IAAM will soon become the name synonymous with a leader for change, and as the organization that led the battle to rebrand these stereotypes. We look forward to many years of making a difference and invite you to join us on the journey!

Tiffany Westrich, Founder & CEO

Tami Caskey Brown, Co-Founder

Amanda John, Co-Founder
The International Autoimmune Arthritis Movement

Year in Review

On May 7, 2011, which was also our Founder & CEO’s 40th birthday, IAAM received notification that we had achieved 501(c)3 nonprofit status!

In July, IAAM officially launched the Media Awareness Hotline, the first outlet ever established for patients to report false or incorrect information in publications or broadcasting.

On October 12th, World Arthritis Day, IAAM hosted a 36-hour online, interactive Awareness Marathon.

In June, IAAM Founder & CEO joined other IAAM Volunteers as they walked in the Magic Mountain Arthritis Walk for Jordan’s Pink Angels. IAAM supplied the entire team with silicone awareness bracelets to show our support of the event and the Arthritis Foundation.

In September, the Media Awareness Hotline rallied a plea to Dr. Phil McGraw to publically retract an incorrect statement regarding obesity in children leading to Rheumatoid Arthritis. Supporters came together and took action resulting in over 500 emails being sent, which helped us to successfully reach our goal in just 72 hours. This initial rally led the way to the official retraction made by Dr. Phil on his public blog two and a half weeks later.

November and December were big months for IAAM! Four IAAM volunteers, including Founder and Co-Founder, flew to Washington DC with the American College of Rheumatology as Patient Advocates. In honor of our Global Network initiative, in which IAAM supports and advocates for other nonprofits in the industry, we decided to focus on Ankylosing Spondylitis and therefore gave a beneficiary donation from our proceeds to the Spondylitis Association of America. IAAM also launched the first and second in a series of Awareness Posters. This Awareness Poster campaign, which will continue in 2012, began with Juvenile Arthritis and Ankylosing Spondylitis.
2011 will go down in history as the year a nonprofit was created to break the stereotypes of the word “arthritis” by rebranding the verbiage and by connecting the world of autoimmune arthritis in a way never before achieved.

Since our inception in May of this year, IAAM has already begun making huge strides in the Autoimmune Arthritis community. Just for starters, the term “Autoimmune Arthritis”, which was coined by IAAM in 2009 while still only a Movement for Awareness, has since been adopted by other nonprofits, bloggers and patient advocates around the world. So we are well on our way to changing the way people categorize these diseases! In addition to breaking ground regarding “arthritis” verbiage, we have begun working to educate those who advertise and write about these diseases by forming the first ever Media Awareness Hotline. This hotline is currently an online program that provides patients with a venue through which they may report any article, advertisement, column, broadcast or publication that provides false information about any strand of Autoimmune Arthritis. Once submitted, IAAM staffs the case with a team who works diligently to make contact with the author/entity and request correction of the misinformation through revision and/or education. We have already had success in getting retractions or edits in 90% of the cases we have pursued, including playing a large part in the recent public retraction by Dr. Phil McGraw regarding a statement he had made naming obesity as a cause of an autoimmune-type arthritis. We also have a mobile application in the works for the Hotline so that patients will be able to report misinformation from anywhere, any time it is discovered.

In addition to our Awareness initiatives, IAAM has started the “Global Network”, an initiative designed to bring the entire world of Autoimmune Arthritis resources together — from other nonprofits and organizations to businesses — so that we may join forces as necessary in order to create a greater impact towards change. In saying this, IAAM does not compete with other nonprofits, we are designed to work with them while supporting and promoting their causes. Our belief is that by supporting and advocating for others we will inevitably broaden the overall understanding, and thus awareness, of Autoimmune Arthritis. We have already formed relationships with dozens of US-based organizations, nonprofits and businesses, as well as some in the UK, Canada, New Zealand and Spain. In 2012, we hope to maintain and strengthen our existing connections while developing additional partnerships for change.

We’ve only just begun, but we are already making history. We can only imagine what is in store for the future!
Autoimmune Arthritis is not “Arthritis”

Autoimmune Arthritis* diseases are classified, according to IAAM, as chronic, systemic, inflammatory autoimmune diseases primarily affecting the joints and are caused by a malfunctioning immune system. While joint involvement is a primary factor, because they are systemic (whole body), they also typically affect the connective and soft tissues and even organs.

“The literal definition of “arthritis” means ‘joint pain’”, explains IAAM Founder & CEO, Tiffany Westrich. “Therefore, in order to change decades of misconception about diseases such as those under the Autoimmune Arthritis umbrella, we must first concentrate on our verbage by expanding on the term ‘arthritis’. These diseases aren’t JUST arthritis. They are serious, and sometimes life-threatening, diseases that can cause permanent disability in patients who are not properly diagnosed and treated early. They need to be respected as such.”

The word “arthritis” is actually synonymous with Osteoarthritis, a degenerative joint condition caused by wear and tear, age or injury, and localized in the weight-bearing joints. Most people will, at some point in their life, will develop Osteoarthritis. Typically, onset is over the age of 55. Approximately 28 million people in the United States alone suffer from this type of joint pain. The 300,000 children who suffer from arthritis are not included in this number because they do not get Osteoarthritis. They get Autoimmune Arthritis.

As mentioned previously, Autoimmune Arthritis is the name for a group of diseases that are the result of a malfunctioning immune system and the pain and destruction they experience are the result of inflammation, not degeneration.

As compared to OA, in the United States, the combined total of patients suffering from Autoimmune Arthritis (as classified by IAAM*) is under 10 million. Onset for children is typically between ages 7-9 and between ages 20-40 for adults. Due to the fact that an estimated 50% of patients may experience complete disability within 10 years after onset if not properly treated, early diagnosis is essential. Without proper awareness of these diseases and the differences they have with respect to degenerative arthritis, we will never obtain the proper funding for research and eventually, a cure.

*IAAAM has partnered with a team of Rheumatologists to determine which diseases fall under the umbrella of “Autoimmune Arthritis”. Those listed here were determined to share the most symptoms and treatment recommendations. We will continue working with the Rheumatology Board to expand this list of Autoimmune Arthritis disease and in addition to add a list of related diseases that do not fall under this primary umbrella.

Current diseases classified as Autoimmune Arthritis diseases, according to our Rheumatology Board are: Rheumatoid Arthritis, Still’s Disease, Psoriatic Arthritis (PsA), Ankylosing Spondylitis (AS), Sjogren’s Syndrome (SS), Systemic Lupus Erythematos (SLE), Juvenile Arthritis (JA), Mixed and Undifferentiated Connective Tissue Diseases (MCTD/UICD).
IAAM was founded due to a Movement that simply would not lose momentum. Once it was on the path to becoming an official nonprofit, volunteers began coming forward from states around the United States and countries all over the world including New Zealand, the UK and Canada. As a result of this widespread interest and desire to participate in our movement, we decided to become a nonprofit. In line with that in October 2010, a Board of Directors was chosen, in addition to a Rheumatology Board, and the IAAM Founders went to work. January 2011 we started our initial training program. They began creating a foundation designed to run as a networked nonprofit, which aspires to be a part of a much bigger system of organizations and individuals that pool resources and work together to reach common goals. In addition, IAAM is 100% created and run by those who are affected by Autoimmune Arthritis, so flexibility in the work place is a necessity. We addressed this by eliminating offices and instead utilizing the latest advancements in technology, thus enabling staff and volunteers to work virtually from anywhere in the world at any time of the day they choose. This format easily allows for global contribution, as communications are accessible twenty-four hours a day seven days a week. In January 2011, we started our initial training program to ensure volunteers were well versed on our mission so that they would be able to promote IAAM and to actively start participating in our initiatives and programs.

The Officers. Tiffany Westrich, Amanda John and Tami Caskey Brown are the Founders and Officers of the organization. All three converse on a regular basis, assuring all programs and initiatives are running at their highest levels of productivity. However, in saying this, although we have ‘officers’, IAAM encourages transparency within the organization, so whether it is the CEO or the newest volunteer, all voices and opinions are listened to and considered important. IAAM CEO, Ms. Westrich, designed and runs the training program, so all volunteers first develop a relationship with her prior to getting to know the rest of the team.

The Volunteers. IAAM volunteers participate in a three-month online training session which includes a small public awareness project prior to graduating to official IAAM Volunteer status. Once trained, IAAM encourages volunteers not
The Machine Behind the Scenes (cont’d)

only to assist with our current programs, but also to utilize IAAM as a platform to launch any of their own ideas that fall under the mission and goals of the IAAM umbrella.

Teamwork. IAAM is a team, from collaboration to decision making, we listen to, analyze, encourage and create solutions. If volunteers write Blogs, we showcase it. If they put in extra hours on one of our existing campaigns, we publically recognize their efforts.

In addition to running the organization, because we are also patients living with the diseases, our volunteers interact regularly within the social networking communities that are set up for those suffering with these diseases. As a result, we are continuously learning the trends, desires and needs of those we are trying to help. This allows us to create the most accurate and necessary programs within the autoimmune arthritis community.

Transparency. IAAM runs as a virtual organization, without chapters or physical office locations. So in order to provide patients with additional interaction and the opportunity to become more involved at home, we have set up a campaign called “Follow the CEO”. Run on Facebook, Twitter and YouTube, this campaign allows supporters to not only keep abreast of what is occurring behind the scenes on a day to day basis. In addition, the video posts provide more information regarding how to be more involved with our current programs. With this initiative, it will be easy to follow and interact with IAAM staff and volunteers. To learn more about the “Follow the CEO” program, you can visit: www.facebook.com/TiffanyWestrichIAAM, www.twitter.com/TiffanyofIAAM, or www/YouTube.com/IAAMovement.

As we move into 2012, we look forward to working with additional groups as well as pushing towards building a bridge of unity among all those organizations in the Autoimmune Arthritis community.
Already, in our inaugural year, IAAM received donations from individuals and businesses which helped in financing a portion of our start-up costs and initial programs. Without your support, IAAM would not be able to provide programs or work towards achieving global awareness. So we thank you, those supporters that make all of this possible.

Special thanks to:

All of the supporters who donated and participated in our November Global Auction. IAAM was able to net $7,200 due to your generosity.

We would like to give additional recognition to the companies who donated to our auction and whose items collectively raised over two-thirds of the proceeds:

- Dexter Duoglide
- Yoga Accessories
- Capes
- Obaji Medical Skin Care
- Kameleon Jewelry
- Allison Austin Designs
- Beau Monde Restaurant
- The Feeding Edge
- Erica’s Tarot Card Readings

- Switchback Ridge Winery
- Miracle Carpet Care
- The Back Sac
- FloridaHolidayHomes4u.com
- Imaginative Beading
- Trueblood-Online.com
- scotiafarmgirl.etsy.com
- Paul Lambie Photography
- ASAP– the Ankylosing Spondylitis Awareness Project

- Massage Heights
- Lynns’ Designs
- Pure Posh Salon
- Bliss Boutique Online
- Felecia and the Dinosaur
- Boardwalk Bight
- Digiditions.com
- Moonlight Mandalas

Thank You: Donor Recognition
2012 will mark the first year that major focus is brought to Autoimmune Arthritis diseases and IAAM will be the organization who will make that happen.

Global Awareness. In December 2011, the IAAM Board of Directors approved the establishment of World Autoimmune Arthritis Day as a day to focus attention on the differences between Autoimmune Arthritis and other arthritis conditions. May 20th was selected for two reasons. First, because it falls within National Arthritis Awareness Month. Second, because it happens to be the date of the first solar eclipse of the 21st century. We feel that this will be symbolic for the magnitude of change we see in the future in the lives of Autoimmune Arthritis sufferers.

The “Age of Arthritis”. The average age of onset in Autoimmune Arthritis in children is 7-9 and 20-40 in adults. IAAM will highlight arthritis-age awareness by focusing heavily on Juvenile Arthritis in 2012. From video campaigns and junior bloggers, the world will begin to meet the youngest members of our Autoimmune Arthritis family.

The Hotlines. In 2011, IAAM launched the first ever, Media Awareness Hotline, designed as an outlet for patients to report published or broadcasted misinformation in the media. Equipped with a team of volunteers, IAAM creates a Case File for each submission, then works towards correcting the misinformation in a professional and educational manner. In 2012, we will continue this initiative and expand on it with the addition of a mobile app, which will expedite reporting capabilities.

We will also launch a similar initiative, the Medical Awareness Hotline, that will allow patients to report medical professionals who are seemingly misinformed about their disease.

We’re On the Air. While IAAM is doing much for awareness in regards to creating understanding for the general public, beginning in March 2012 we will be engaging in an interactive, educational and fun IAAM Online Radio Show aimed at bringing self-awareness to patients about their disease. Hosted by CEO Tiffany Westrich and a continuously changing co-host who will be selected from existing advocates in the Autoimmune Arthritis community, the show will cover important issues in self-wellness in a unique and entertaining way.
Wellness. Our wellness initiatives focus primarily on wellness as it relates to awareness. This includes awareness of treatments, of ways patients understand their limitations and of the way the medical world understands the Autoimmune Arthritis diseases.

Medical or Holistic?
Autoimmune Arthritis diseases present themselves differently in every person, including the severity of the disease and physical reactions to treatments. What works for one patient may or may not work for another. In 2012, IAAM will work to provide information on the realities of treating Autoimmune Arthritis disease medically or holistically. This initiative will attempt to dispel myths that a simple diet overhaul is enough to affect disease progression in these serious illnesses.

Dealing with Limitations
Autoimmune Arthritis patients are most often affected before the age of 40. Experiencing disability at any age is difficult; experiencing it suddenly, which is what often occurs with Autoimmune Arthritis, adds an entirely different layer to the frustration. In 2012, we will focus on self-awareness of limitations and address ways one can accommodate for those limitations.

In addition, you’ll learn tips from patient experts, such as Melinda Winner, RA patient and author of “Cooking with Arthritis”.

Bridging the World of Autoimmune Arthritis to Promote Early Diagnosis
As a result of speaking with thousands of patients around the world, IAAM has realized the many similarities shared between the strands of Autoimmune Arthritis diseases. In some cases, the similarities are so drastic that doctors may shift the diagnosis from one disease to another (for example Rheumatoid Arthritis to Systemic Lupus or vice versa). We have also realized that early on in the disease the symptoms may be so generalized that they often suggest the possibility of many diseases that fall under the Autoimmune Arthritis genre. However due to the uncertainty regarding which strand, the doctor may delay diagnosis altogether. IAAM hopes by charting our findings, we may collectively gather enough information to promote earlier diagnosis. Because treatments for all the strands are similar and it has been proven that early medical therapy is required for the best chance of remission, we hope to lessen the rate of young disability and patient suffering.
As the first and only nonprofit to bring global awareness to the collective group of Autoimmune Arthritis diseases, we are committed to utilizing contributor donations in the most effective and responsible way possible.

In 2011, the International Autoimmune Arthritis Movement and its’ programs were initially funded primarily by our Founder & CEO, Tiffany Westrich. However, in November of this year, IAAM hosted our first large fundraiser which raised enough money to continue our existing programs and to cover a portion of our start up costs and general office necessities.

IAAM used 28% of these funds to continue the initiatives Ms. Westrich originally funded. A small percentage was allocated towards our efforts to fundraise and the remainder was used for office overhead and supplies, as well as software, hardware and other start up costs.

We look forward to moving into our first full year up and running as a fully-functioning global nonprofit organization. We promise to utilize all funds in a manner that will best achieve our goals to create awareness, education and resources for the Autoimmune Arthritis community.

The accounts and financial statements of the IAAM are maintained in accordance with generally accepted accounting principles for nonprofit organizations. You may view a complete copy of our annual financial audit report at http://www.IAAMovement.org.

Tiffany Westrich  Suzanne da Câmara
Founder & CEO  Treasurer
Public Support and Revenue

Contributions: $1,260
Non-operating income: $1,458
Special Events: $8,459

Total Income: $11,177

Expenses

Programs & Services: $2,630
Fundraising: $867
Office & Overhead: $4,140
Start-Up Costs: $1,965

Total Expenses: $9,602