

August 23rd, 2017

Re: Future of the ISDF

Hello Everyone,

As most of you know, I have served as the President of the ISDF for many years, most of them side by side with our founder, Bob Himes, who sadly lost his battle with Still's Disease in 2015. Most of you are also aware that my health has not been so good this past year. Many of our wonderful volunteers have stepped up to help keep the ISDF going – from our online Facebook support group to private awareness and educational events – in the midst of it all our spirit and drive to keep our Still's Disease 'home' has been evident. I cannot thank you all enough for that. Then, as my illnesses continued to worsen, in May of 2017 our friends at AiArthritis (International Foundation for Autoimmune & Autoinflammatory Arthritis) began helping to ease the burdens of this situation by managing our support groups, web site, and boosting our programs for awareness by promoting (and now hosting) Still's Disease Awareness Day on September 7th.

I have struggled not only with my health, but with the fear of what will happen to the ISDF if I can no longer continue the work we have done these past years. Thankfully, together with AiArthritis, we have resolved this problem.

In September, the ISDF will dissolve as an official nonprofit organization, *but we will have a new home at AiArthritis*. They have agreed to continue hosting the online Facebook support group and will one day fulfill our dream to have our website become a Still's Disease Information Center, so all of our resources will remain intact for future use. They also have begun to develop additional research efforts with the National Data Bank for Rheumatic Diseases that I'm confident can take our work to a level even beyond what we were able to do. Also, just as all our years of work with remain, I will too, as I will become an Advisor for Still's Disease at AiArthritis. The primary goal is to make a transition that is as seamless as possible. While it may sadden you to see the ISDF 'go', please understand it's not actually disappearing, but rather relocating to a place where the leadership can preserve our past efforts, embrace our current culture, and catapult efforts to a whole new level. So it's really a new beginning and chapter for our community!

About AiArthritis: AiArthritis is also a patient led, international nonprofit who we have worked with often since they established World Autoimmune/Autoinflammatory Arthritis Day in 2012. We also participated in their Early Symptoms of Autoimmune Arthritis research study in 2013-2015, which logged patient reported early symptoms of 6 diseases to help expedite early diagnosis and access to treatments. They are also extremely active in public policy and raising funds for awareness and research for these key diseases (which includes Still's Disease). Their proven professionalism and sensitivity to patient's



needs has given me the confidence I needed to put our years of work in their capable hands. They also have a very active volunteer program, which several of you I know already participate in; you can continue any volunteer work you were doing with or in honor of the ISDF at their organization. They will welcome you with open arms, I assure you.

While the official turn over and public announcement that ISDF will dissolve and remaining resources and programs housed under AiArthritis will be on September 7th, selected to honor Still's Disease Awareness Day, we wanted to notify you - our community members - first. Upon dissolution, ISDF will be passing along any remaining donations to AiArthritis so that they can continue our work in Still's Disease. I hope that you will also support them by sending your future donations to them. You can learn more about AiArthritis at Guide Star (https://www.guidestar.org/profile/27-1214308#) where they are a Gold Rated organization or at their website at www.AlArthritis.org.

I would like to thank each and every one of you for your help and support over the years. I would also like to extend a very special appreciation to all of the past and present members of the Board. They served tirelessly by helping in any capacity they could. If you know even one presently, or if there is someone you are in touch with that has helped you, we ask that you thank them in your own special way. Again, remember that this is not the 'end' but rather a new beginning for Still's Disease advocacy, awareness, research, and support!

I know you will have questions, so Tiffany Westrich-Robertson, CEO of AiArthritis will be happy to field those for you. Her email is tiffany@aiarthritis.org.

I wish you well with pain-less days, gentle hugs and smiles,

Patricia L. Boerner – aka Melly

International Still's Disease Foundation, Inc. Soon to be Still's Disease Advisor, AiArthritis