

STILL'S DISEASE: RESEARCH & CLINICAL TRIALS

August 31, 11 am EST/USA

A webinar for persons affected by Still's Disease

A don't miss opportunity for patients, parents of juvenile patients, and caregivers to ask questions to the presenters!

**Register for FREE at:
<https://bit.ly/StillsResearchClinicalTrials>**

Can't be there at this time? Register anyway, we will send a link to watch the recording and an opportunity to still submit your questions!

**Tiffany Westrich-Robertson, CEO,
AiArthritis**

Clinical trial participation and shared-
decision making



**Rashmi Sinha, PhD, Founder,
Systemic JIA Foundation**

Current research and its importance in
relation to Still's Disease



Sylvia Hanna, Avalo

"Investigating an anti-IL-18 monoclonal
antibody for Still's Disease (AOSD) and
Multiple Myeloma"



**Jeanette Bachir, Clinical Science
Leader, Sobi**

"Macrophage Activation Syndrome (MAS)
– a Complication of Still's Disease"



**Presented by: AiArthritis, the
Systemic JIA Foundation, and
the Autoinflammatory Alliance**

*In conjunction with Still's Disease
Awareness Day efforts.
#StillsDay #MyStills*



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In conjunction with efforts to promote education and awareness for [Still's Disease Awareness Day](#) (September 7th), and as part of [Autoinflammatory Awareness Month](#) (August), we invited those affected by Still's Disease ([sJIA](#)/Adult-Onset Still's Disease) to join [AiArthritis](#) for a webinar on Still's Disease Research & Clinical Trials.

The following are additional resources and supplemental information about the information presented during the webinar

- **Here's a link to the original recording:** [Still's Disease: Research and Clinical Trials](#)
- **But wait! We weren't done after the first session!** A week later, Tiffany hosted a private RE-WATCH party, where she selected some key points from each presentation, replayed them, and then **explained more about the research - and terms mentioned in the presentations - in easy to understand language. Here's a link to the segmented version of the webinar:** [Rewatch! Of "Still's Disease: Research & Clinical Trials"](#)

Glossary

Glossary contains explanations of
sense, the term



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Glossary of Terms discussed during the webinar (and Rewatch Party).

- **Macrophage activation syndrome (MAS):** a severe complication of rheumatic disease in childhood, particularly in systemic Juvenile Idiopathic Arthritis (sJIA). It is characterized by an uncontrolled activation and proliferation of T lymphocytes and macrophages. ([source](#))
 - **Diagnosis by exclusion (aka “trashcan diagnosis”):** A diagnosis of exclusion or by exclusion is a diagnosis of a medical condition reached by a process of elimination, which may be necessary if presence cannot be established with complete confidence from history, examination or testing. ([source](#))
 - **Refractory:** Refractory disease is defined as failure to attain a predefined target, which is now accepted to be remission or, at least, a low disease activity state. Despite the enthusiastic progress in the field of rheumatoid arthritis pharmacotherapy, few patients are still reaching sustained remission. ([source](#))
 - **Biomarkers:** Something measurable, like blood markers, blood pressure, genetic tests, tissue samples. They do not necessarily define how a person feels or functions, but can lead to questions and answers.
 - **IL (as in IL-18 treatments):** Sounded out: Eye-L - IL is short for interleukin. Interleukins are types of proteins made in response to microorganisms (pathogens) and other foreign substances (antigens) that produce, regulate, and mediate inflammatory and immune responses
 - **Cohort:** Group of people with similar profiles
 - **CRP - C-Reactive Protein:** Inflammation indicator
 - **ESR - erythrocyte sedimentation rate:** Red blood cells
 - **Shared-Decision Making:** The process when a patient gains education about (a treatment/intervention) and then discusses the options (including benefits and risks) associated with use. The conclusion is decided together, rather than relying on the doctor to decide.
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Clinical Trials can be a crucial way to obtain good treatment for Still's Disease. Both sponsors of the webinar Sobi, and Avalo Therapeutics have clinical trials aimed at treating patients in the Still's community.

Learn more about the clinical trials presented:

- Sobi (MAS): Evaluate Efficacy, Safety and Tolerability, PK and PD, of Emapalumab in Children and Adults With MAS in Still's or SLE
 - <https://clinicaltrials.gov/ct2/show/NCT05001737>
- Avalo Therapeutics (IL-18): A Study to Evaluate AEVI-007 in Participants With Adult Onset Still's Disease
 - <https://clinicaltrials.gov/ct2/show/NCT04752371>

If you are interested in learning more about participating in these trials, please let us know, email Katie@AiArthritis.org and we can help!



Tips on talking to your physicians about clinical trial participation:

As mentioned in the Glossary of Terms above, Shared-Decision Making involves specific steps, regardless of the intervention being assessed (i.e. treatment, non-pharmacologic therapy, entering a clinical trial or not, etc.). The first step in this process is education. We provided a lot of that in our webinar, including recommending to learn more about clinical trials by visiting the following sites: [US Food and Drug Administration](#), [European Medicines Agency](#)

So, now that you've had some education about trials and may be considering if they are right for you, the next step is to ask yourself "*Why am I considering this?*" Some possibilities are:

- You have tried other therapies and are not having success feeling better ("refractory" disease)
- You cannot afford access to treatments and this may provide those resources
- You are interested in trying a new therapy in a controlled environment (where you are closely monitored)

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Regardless of the reason, once you decide you may want to discuss this with your doctor, get prepared. Here are some tips:

- If you have a portal (online means of communicating with your rheumatologist/doctor primarily treating your disease), let them know that you are considering a trial. Provide a couple of reasons why. *You do not have to wait until you are face to face in a scheduled appointment to bring up this topic, especially since trials recruit for a set period of time.*
 - If you know about a trial already, and are interested in potentially joining, send a link to that trial with your message.
- If you do wait to talk to your doctor at your next visit, prepare ahead of time. Your doctor will want to know why you are thinking about participation, have your reasons ready.
- Listen to what your doctor says. If your disease is fairly controlled, it's possible your doctor may not recommend trial participation at this time. If you are in a transition between treatments, never started any treatments yet, or have a history of not responding well to treatments, your doctor may feel this is a good option.
- Ask your doctor if they are aware of any trials, or if you have one already in mind, ask if they would be willing to look into it more. Then, together, you can determine next steps. This will involve you and your doctor weighing the pros and cons of participating - but eventually you'll come to the best decision for you!



For those affected by Still's disease, we welcome you to join our AiArthritis Voices program.

The AiArthritis Voices Program was developed so our organization can connect you with opportunities to participate in a wide array of activities - as equals, alongside other patients and stakeholders (researchers, companies, government, medical community, etc) - so, together, we can solve problems that impact education, advocacy, and research. Examples include learning activities, surveys, webinars, live events, input on our award-winning AiArthritis Voices 360 Talk Show and more!

You can sign up at <https://conta.cc/2WDk8yP>

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Learn more about the presenting nonprofits by visiting their websites:

- www.AiArthritis.org
- www.SystemicJIA.org
- <http://Autoinflammatory.org>

Thank you for your interest and your time. If you have any further questions, or if you have any comments or feedback please let us know by contacting Stills@AiArthritis.org

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