

\$10-million grant will help researchers find the right drug to control arthritis in kids like Ava

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Funds will allow interdisciplinary UCalgary team to transform the treatment of childhood arthritis

By Nancy Whelan, McCaig Institute for Bone and Joint Health

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Ava Morgan has been living with juvenile psoriatic arthritis since the age of seven. Doctors have struggled to find the right medication for her. A new \$10-million grant will help determine the best course of treatment for kids like Ava. *Photo by Don Molyneaux, for the University of Calgary*

When Ava Morgan was seven years old, she began complaining about sore knees. Within a few months, her knees, ankles and shoulders were swollen, and she was having trouble walking. A visit to paediatric rheumatologist Dr. Susa Benseler and a series of blood tests confirmed Ava had psoriatic juvenile arthritis.

Dr. Benseler started Ava on medication immediately, but finding the right drug and the right dose was difficult. After several years of trying different therapies and struggling with side effects, Ava is now trying a type of drug called a biologic.

"We still have many appointments to get everything figured out and decide what the future plan is for Ava. She'll be starting on a new biologic and, fingers crossed, this gets her back on track and we can get her arthritis under control," says Ava's mom, Christeena Morgan.

Arthritis doesn't just affect seniors

More than 24,000 children in Canada live with the painful, chronic disease that can cause fevers and destruction of joints, leading to a life of permanent disability. A class of powerful drugs called biologics can dramatically reduce joint inflammation and pain and prevent joint damage in the longer term, though they also come with a risk of side effects.

The drugs can cost as much as \$400,000 per year, and children may only qualify after traditional treatments have failed, by which time permanent damage may have occurred. Evidence shows that early short-term biologic treatment, even for as little as three months, can result in long-lasting disease control in the most severely affected children.



Childhood arthritis team members and Genome Alberta representatives at the Genome Canada announcement Jan. 23. Back row, from left: Marv Fritzler, Gijs van Rooijen (Genome Alberta). Front row, from left: Gillian Currie, Ana Sepulveda, Harleen Ghuttora (Genome Alberta), Deborah Marshall, Marinka Twilt, Dianne Mosher and Susa Benseler. *Photo by Riley Brandt, University of Calgary*

\$10 million grant will support treatment for children with arthritis

A network of Canadian researchers and international partners, including several UCalgary investigators, has received \$10 million in funding from Genome Canada, in partnership with the Canadian Institute of Health Research (CIHR) and numerous other co-funders.

The new funding will allow researchers to identify which children need biologics, which biologic will work best for an individual child, and when the biologic can be safely stopped. Researchers will also work with health service policy-makers to assess the socioeconomic benefits of these strategies, looking at costs of treatment, quality of life, time lost from school, lost employment opportunities, and lost work time for the parents of these children.

The grant will also allow the team to develop the first genomics-based, low-cost biomarker blood test to rapidly identify the best treatment for each child, completely transforming the treatment of childhood arthritis. A smartphone- and web-based system of eHealth apps will establish an integrated network of patients, physicians and researchers. This will allow researchers to evaluate the risks, benefits and costs associated with these medications, which will inform health-policy decision-makers about cost effectiveness, patient preferences and affordability.

“People don’t know that kids can have arthritis, and that it can be a debilitating disease. If children are not treated quickly and effectively, they can be disabled permanently,” says Benseler, co-lead of the project and a professor in the Cumming School of Medicine (CSM). “The goal of our network and this project is to rapidly diagnose arthritis in children, understand the disease in each individual child and target joint inflammation in the safest and most effective way — no more trial and error, no more wasting time.”

“Although the treatments can be expensive, the lost productivity of children disabled from their arthritis, as well as that of their parents, may exceed the annual costs of effective medications.

Thus, precise targeting of disease, including decisions to start and stop treatments, in a timely manner, is essential,” says Deborah Marshall, PhD, health economic lead on the project and a professor in the CSM. “This grant allows us to build a knowledge base and measure and quantify the outcomes, which will not only have an economic impact, but could save or improve the lives of children with arthritis.”

Large UCalgary interdisciplinary team involved

The researchers on this project include an interdisciplinary group of scientists from the CSM and the joint paediatric and adult care team of the Division of Rheumatology in the Department of Paediatrics:

- Susa Benseler, MD, is a paediatric rheumatologist and professor in the Department of Paediatrics at the Cumming School of Medicine and member of the Alberta Children’s Hospital Research Institute and the McCaig Institute for Bone and Joint Health. She is the co-lead of this grant.
- Marvin Fritzler, MD, PhD, is a professor in the departments of medicine and biochemistry and molecular biology, a member of the McCaig Institute for Bone and Joint Health and director of Mitogen Precision Diagnostics. His research team will provide the identification of specific biological subtypes of the disease.
- Deborah Marshall, PhD, is a professor in the departments of community health sciences and medicine, Canada Research Chair in Health Services and Systems Research, Arthur J.E. Child Chair of Rheumatology Outcomes Research, and member of the **McCaig Institute of Bone and Joint Health**, the O’Brien Institute for Public Health and the Alberta Bone and Joint Health Institute. She is the health economics leader of



“Hockey is her true passion, and she wants nothing more than to play hockey and ‘be normal’,” says Ava’s mom, Christeena Morgan. *Photo courtesy Morgan family*

the project and will measure the economic impact of precision medicine for childhood arthritis, quantify patient preferences and develop mathematical models that will guide health policy.

- Marinka Twilt, MD, PhD, is an assistant professor in the Department of Paediatrics, a rheumatologist and member of the Alberta Children's Hospital Research Institute.
- Dianne Mosher, MD, is an adult rheumatologist and professor in the Department of Medicine at the Cumming School of Medicine and a member of the McCaig Institute for Bone and Joint Health.
- Gillian R. Currie, PhD, is an associate director of Health Economics Research with Deborah Marshall's team, an adjunct associate professor in the departments of community health sciences and paediatrics, and a member of the Alberta Children's Hospital Research Institute and O'Brien Institute for Public Health.



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