



Thank you for joining us this fall season for the AMC Research newsletter, we are always so grateful to have you. Just as the leaves are changing to warm colours of red, yellow, and orange, there are exciting and new changes in our work and the field of AMC that we would love to share with you.

In this newsletter, we will be sharing the start of a centralized place for you to find all resources AMC-related, wonderful passion projects from people in our very own AMC community, our second virtual webinar, and a crossword to challenge your knowledge.

See what might interest you, or learn something new in this fall newsletter! We encourage you to read on and tell us what you would like to see in our next newsletter.

AMC Resources Made For You

One of our goals and projects that we hope to work on is creating a simple, compiled list of resources that you can quickly access on our website. As exciting developments arise and as new resources are compiled, we hope to polish and build this list to be as specific relevant and helpful to your needs.

We encourage you to send anything that you feel might be appropriate to include in this resource document to bonita.sawatzky@ubc.ca. [This list of resources can be accessed here](#), and will continue to grow on our website.

AMC Community Spotlight: Meet Misha!



Tell us a little about yourself.

My name is Misha, and I was born in Peru in 1984 and diagnosed with arthrogryposis not more than a month later, in which all four of my limb are affected but I am still able to walk and be very independent. Having lived a very fulfilling life with a job, a wonderful husband and a great support network, it was not until I was 28 that I met someone else with AMC for the first time at a conference. For the first time, I realized that something was missing in my life by meeting someone else like me, and decided that I wanted to make a change in the AMC community.

What is "[The Dream Walker Project?](#)"

The project is one of love and community, serving as bridge between families. Although I was fortunate enough to meet someone else with AMC at a conference, I not only wanted to connect family on a deeper level beyond conferences, but also recognizing that not all families are able to go to these already scarce conferences. In fact, the oldest person I met that had yet to meet someone else with AMC was 69 years old! My first start in promoting AMC Awareness began with my blog in 2012, despite only hoping to reach at least one family across the world, ended up reaching families all across the Philippines, USA, Brazil, Europe, and more. However, knowing I wanted to take this a step further, my spouse and I rented a car in 2017 and went on an adventure to visit our first 30 families across the USA and connect people living with AMC with one another and sharing unique lived experiences. In the summer of 2022, we visited 197 families in the USA, and 97 families in Canada this year. This project and the way it has connected myself and other AMC community members has been invaluable in creating support, encouragement, and hope.

On our trip we take the old lady aka the AMC car, an 98' Buick that was donated by an AMC family, who is our travel companion who collects the hand prints of those we visit and that takes a visual sense of community wherever we go. So far, the car has travelled over 60 thousand miles or 96 thousand kilometers!

Finally, I would like to add that we do this by the hand of the AMCSI through the international ambassador program and with the help of our community through their donations and fundraisers.

What are some of the highlights of your trip this summer?

There are no words or singular moments that could describe what this summer trip meant to me this year. Even having come from Peru, where people are often very open in showing love but I felt like there was something in Canada where everyone was so nice, always willing to help, and interested in learning about the project! Meeting families, support groups, and other researchers and health care professionals, especially Dr. Judith Hall and Dr. Bonita Sawatzky and being able to hear their expertise was a once in a lifetime opportunity.

What are your plans for next summer?

Next summer, I have already had more than 60 families in the USA reach out asking for visits which I hope to accomplish in about a month's time. Heading back to Peru, I am excited to share that I will be excitedly traveling across Europe, making a quick pit stop in Canada for the AMC symposium, before heading back to Europe to continue the Dream Walker project.

What plans do you have for the Dream Walker Project moving forward?

This is a question I always get asked, and a fair one as there are many challenges and considerations that need to be taken into account - financially, feasibility, and even age. However, my goal is to keep going for as long as we can in the hopes that I can look back and say we have reached all corners of the world and make a worldwide community across all continents. In the end, I want to reach as many families as I can to support hope, integration, and community for AMC families, and inspire others to do the same.

What advice do you have for others living with AMC, or those that want to get involved?

For those living with AMC, I recommend finding a support group that understands your needs, whatever that be the AMCSI or something else. These groups are absolutely important in encouraging other people with AMC and possibly even changing their lives. For those that want to get involved, I say do whatever you can! For example, something I personally adopted was using the full name of arthrogryposis multiplex congenita as the condition is not the first search result when you look up AMC. In addition, I would recommend doing whatever you can to engage with social media, reaching out to your following, and taking whatever opportunity to educate people as a little lesson can grow and expand tremendously.

What do you do for fun along your travels?

Given our travel schedule, we unfortunately do not have time to sightsee or even eat some days. However we make the most of our trips by trying to take the scenic route, and blast music listening to anything and everything we can. Particularly, Tim Horton's or Timmies as the Canadians call their coffee franchise, had a special place in my heart during our trip this summer.

Where can we reach you if we have more questions?

You are more than welcome to reach out to me on social media @mishadreamwalker on all platforms (Instagram, Facebook, Tik Tok, and threads), or by email at misha@mishadreamwalker.com. If you want to see more of the work that I do, follow, and support the Dream Walker Project, [you can visit the website here](#). Whether you're a medical scientist, in research, or just interested and want to be part of the journey, I would be more than happy to chat!

Save the Date: 2nd AMC Webinar

WEBINAR: NOV 29, 12 PM PST
Arthrogryposis and Wheeled Mobility
Hosted by Dr. Bonita Sawatzky & Dr. Megan MacGillivray

Hear from experts on how wheeled mobility impacts AMC



**Dr. Bonita
Sawatzky**

ASSOCIATE PROFESSOR,
UBC ORTHOPEDICS



**Dr. Ben
Mortenson**

PROFESSOR,
UBC OCCUPATIONAL THERAPY



**Misha
"Dream" Walker**

AMC ACTIVIST,
MOTIVATIONAL SPEAKER



**Kyrby
Brown**

ADAPTIVE SPORTS
ACTIVIST



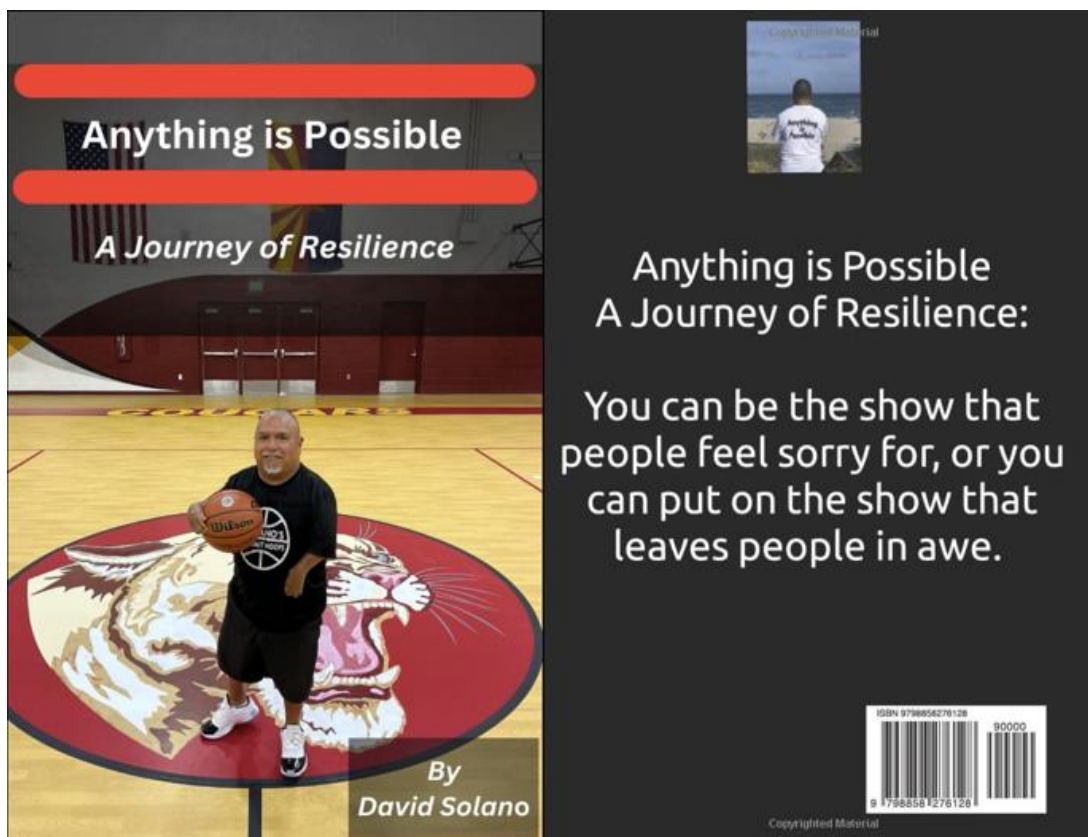
SCAN THE QR TO REGISTER!



Join us for our 2nd Virtual Webinar on Arthrogyriposis and Wheeled mobility November 29th at 12 PM PST and hear from our expert panel of speakers and gain valuable insights from the University of British Columbia's [Dr. Bonita Sawatzky](#) and [Dr. Ben Mortenson](#), plush [Misha "Dream" Walker \(Peru\)](#) and [Kyrby Brown \(UK\)](#). **We guarantee it will be 'wheely fun!'**

We are so excited to share this opportunity with you, and wanted to kindly ask to send in your questions so that we can prepare to answer them the day of the webinar. [Please find the form to register and submit questions here.](#)

A Story of AMC and Resilience

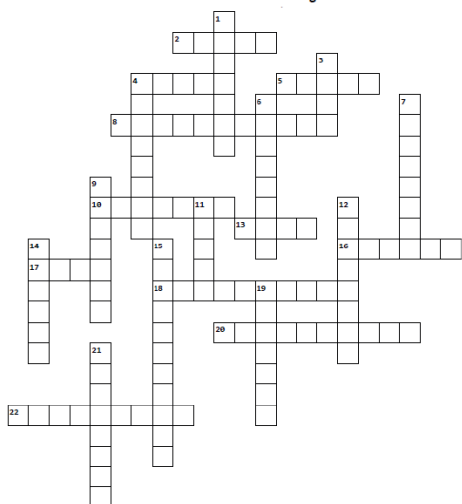


From our very own guest speaker from our webinar on [Arthrogyriposis in Sport and Exercise: How to Become More Active](#), David Solano shares his struggles and achievements living with AMC. As a teacher of 25 years, husband and father to 2 daughters, and president of "No Limit Hoops," a free basketball program, his unique life experiences is a testament to both resilience and determination.

[You can support David and read more about his journey through his book here.](#)

AMC Crossword: All Things Wheelchair

AMC November Crossword: All Things Wheelchair



Across

2. A surface of which one end or side is at a higher level than another; a rising or falling surface.
4. Firm and stable in shape; not liquid or fluid. Some tires are pneumatic and some are "st" which reduces punctures but makes them heavier and harder to wheel with.
5. release A feature that allows for easy removal of attached components for convenience and transportation. (2 words)
8. A material consisting of thin, strong crystalline filaments of carbon, used as a strengthening material, especially in resins and ceramics. Can make products exceptionally strong with great energy dampening. (2 words)
10. A padded or supportive surface located on the sides of chairs to provide comfort and support for the user's arms.
13. rim The circular hand grips on the out edge of the wheelchair wheel, allowing the user to propel themselves by pushing on them.
16. Small swiveling wheels located at the front of a wheelchair that aid in maneuverability and turning.
17. The shaft on the wheels of a wheelchair rotates, allowing them to turn.
18. A chair mounted with wheels for use as a means of transport by a person when walking is not feasible.
20. A system that absorbs shock and impacts from uneven terrain, providing a smoother and more comfortable ride.
22. Containing or operated by air or gas under pressure.

Down

1. A design feature that allows the wheelchair to be collapsed for storage or transport.
3. A rubber covering, typically inflated or surrounding an inflated inner tube, placed round a wheel to form a soft contact with the road.
4. The front/back angle at which the wheelchair's seat is positioned, which can affect the user's posture and weight distribution (2 words).
6. A lightweight and strong metal often used in the construction to reduce weight, providing energy dampening without compromising strength.
7. The support for a seated person's feet.
9. Container consisting of one or more cells, in which chemical energy is converted into electricity and used as a source of power.
11. Each of the bars or wire rods connecting the centre of a wheel to its outer edge.
12. The part of the wheelchair that supports the user's back, providing comfort and stability.
14. The angle at which the rear wheels are positioned, which can affect stability and the ease of turning.
15. An electric or battery-powered system that provides additional force to assist the user in propelling their wheelchair, making it easier to move. (2 words)
19. A supportive padding or material placed on the seat of a wheelchair to provide comfort and prevent pressure sores.
21. An advanced and lightweight material to achieve exceptional strength-to-weight ratios, but more brittle than titanium.

If you would like to complete your own crossword, click the image above or [click here for your own printable copy](#).

[Answer Key to November Crossword](#)

Acknowledgments | Contact Us

We would like to thank Arthrogryposis Multiplex Congenita Support, Inc. (AMCSI) for supporting our knowledge translation efforts and enabling us to get the most up-to-date research findings to you!

Finally, we would like to thank all of you, as your feedback has helped us push for more newsletters, webinars, and content relevant to adults with AMC! If there is anything else you would like to see, send your ideas to us at bonita.sawatzky@ubc.ca and we will see how we can explore these further in our next newsletter and other forms of content creation.



THE UNIVERSITY
OF BRITISH COLUMBIA

