

JIA Family Resources



PR-COIN RESOURCES

JIA Helping Hands Handbook – a JIA handbook for patients and their families www.pr-coin.org/other-resources

Accommodation Toolkit – information on accommodations and ADA laws for grade school, college exams, college, the workplace, and in public www.pr-coin.org/tools-resources-patient-families

College & JIA – information on attending college with JIA www.pr-coin.org/tools-resources-patient-families

PR-COIN Joint Journal – an e-newsletter for JIA patients and families www.pr-coin.org/contact-families

Connect with PR-COIN on Facebook (@PediatricRheumatologyCOIN) and X (formerly Twitter @_PRCOIN)

ARTHRITIS FOUNDATION RESOURCES

JA Power Pack – a backpack filled with information and resources for JIA patients/families. It is only available to Continental US residents. www.arthritis.org/juvenile-arthritis/get-your-ja-power-pack

JA Family Summit – an annual 4-day conference for children (aged 6 months to 30 years) with JIA and their families (including siblings) held each summer that offers educational sessions, networking sessions, and kid/teen/young adult programming. Location changes every summer. A limited number of travel scholarships/awards are available. www.arthritis.org/events/ja-familysummit

JA Camps – camps for children diagnosed with JIA. Camps are traditional summer camps but with adaptations to make programming more accessible to campers with JIA and with activities that focus on helping campers gain a better understanding of their arthritis. Some areas also offer JA Family Camps, which are weekend camps for the whole family. www.arthritis.org/events/ja-camps

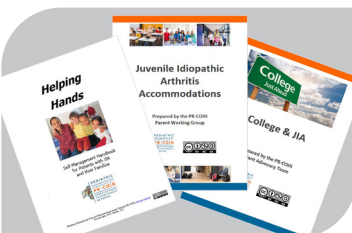
Advocacy – advocating with the Arthritis Foundation is a great way for patients with JIA to learn to share and own their story. The Arthritis Foundation provides training and hosts Advocacy Summits in DC and Capital Days where you can connect with others diagnosed with arthritis and advocate at the federal or state level. www.arthritis.org/advocate

Live Yes! Connect Groups – there are virtual support groups and a handful of local support groups for parents of children with JIA. <https://connectgroups.arthritis.org/groups/viewall>

WTCA/JBR – the Walk to Cure Arthritis (WTCA) and Jingle Bell Run (JBR) are annual fundraisers for the Arthritis Foundation and are also a good way to connect with local JIA families.

www.arthritis.org/events/wtca or www.arthritis.org/events/jbr

Connect with the Arthritis Foundation on Facebook on their main page (@ArthritisFoundation) and on their state pages (for “Arthritis Foundation” followed by your state name). They also have a page for the JA Family Summit, which used to be called the JA Conference (@JuvenileArthritisConference)



CASSIE + FRIENDS RESOURCES (for families in Canada)

Youth Mentorship Program – JIA patients connect with trained mentors cassieandfriends.ca/youthmentorship

Future Leaders Program – JIA patients aged 17+ commit to a one-year program where they train to be a youth mentor and launch their own special project <https://cassieandfriends.ca/yn>

Run/Walk – join a local run/walk event and connect with other families <https://cassieandfriends.ca/run/>

Juvenile Arthritis Canada – a private Facebook group for Canadian families living with juvenile arthritis that is run by Cassie + Friends www.facebook.com/groups/189908714401014

SOCIAL MEDIA RESOURCES

Note: these private groups are not medical forums. They are for support and connections with other families and are not to be used as a substitute for medical advice. Search for the group or use the link.

Mothering Juvenile Arthritis – for female caregivers of JIA patients www.facebook.com/groups/235825606526802

Juvenile Idiopathic Arthritis (JIA) Caregiver Support Group – for anyone caring for a child with JIA www.facebook.com/groups/1706892562899907

JA Dads – The Tribe: It takes a Tribe to Raise a Kid with JA – for male caregivers of JIA patients www.facebook.com/groups/512426245502712

Kids with Uveitis – for caregivers of children diagnosed with uveitis www.facebook.com/groups/kidswithuveitis

TMJ/ JIA Parents – for caregivers of children diagnosed with JIA who also have jaw involvement www.facebook.com/groups/843075322431782

SJIA Systemic Juvenile Idiopathic Arthritis Parents Network – for caregivers of children diagnosed with SJIA www.facebook.com/groups/SJIAParents

Social Media Hashtags - #StrongerThanJA #KidsGetArthritisToo #JIAWarrior

AWARENESS RESOURCES

World Arthritis Day – recognized annually on October 12

World Juvenile Arthritis Day – recognized annually on March 18

Juvenile Arthritis Awareness Month – is July in the US and March in Canada

Arthritis Awareness Month (all types of arthritis) – is May in the US and September in Canada

Blue Ribbon – the awareness ribbon for JIA is royal blue

PODCASTS

Live Yes! With Arthritis – The Arthritis Foundation’s podcast hosted by patients, for patients

Take a Pain Check – features patients, medical professionals, and more

Those Girls With Arthritis – two young adults navigating life with arthritis

CARRA – The CARRA (Childhood Arthritis and Rheumatology Research Alliance) podcast is available on standard platforms and is also available at <https://carragroup.org/blog-category/podcast/>

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