

Our Network Mission

- To promote the health and welfare of 9pminus families
- To advise and aid parents/guardians of challenges in raising a child with special needs
- To offer a networking format specifically addressing this rare chromosome anomaly
- To address social policy issues and conditions limiting the full potential of individuals with 9th chromosome disorders
- To encourage research related to the “p” arm of the 9th chromosome within the Network population
- To serve as a home of information gathering and distribution regarding this rare chromosome deletion
- To support Network family interaction by publishing annual Yearbooks, supporting Family Reunions, encouraging fundraising events

MISSION STATEMENT

The Chromosome 9pminus Network is a nonprofit, parent-based support group with a mission to improve the lives of families affected by 9p Deletion Syndrome by connecting families, offering knowledge, and improving access to information about this rare genetic disorder.

**For more information,
please contact:**

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Appleton, WI 54912
~ or ~
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What in the World is 9p-?

*Chromosome 9pminus Network
P.O. Box 524
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**www.9pminus.org
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The Chromosome 9pminus Network is a place for families to connect and share information regarding individuals with 9p Deletion syndrome, also known as “9pminus”, “Alfi’s Syndrome”, and/or “Monosomy 9p”. This syndrome is an extremely rare chromosome anomaly so many families with a loved one diagnosed with a 9p Deletion are left feeling isolated. Thanks to this Network, families now have a place to turn!

This Network is an international non-profit organization that solely relies on donations and has no paid employees. All Board of Directors as well as Committee members is volunteer parents or caregivers.

The Network strives to educate, foster hope, and develop a greater understanding amongst its members and the community at large.

Chromosome 9pminus Board of Directors:

President: Jacqueline Bair, NY
Vice President: Kristen Nazworth, LA
Secretary: Jill Holtzmann, MO
Treasurer: Kris Constantino, IL
Director: Cindy Kutz, LA
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07/14

People with 9p- have so many different levels of varying issues that it is difficult to provide a comprehensive list of traits. The following outlines the most common characteristics observed in 9p- individuals. It is important to note that not all of these characteristics will be found in those diagnosed.

Typical Characteristics:

Global Developmental Delays
(i.e. Delayed Walking, Speech)
Intellectual Disability
Hypotonia
Trigonocephaly
Small Mid-face
Small Mouth
High or Cleft Palate
Small Ear Canals
Narrow Ears & Attached Lobes
Up slanted Eyes
Narrow Hands and Feet

Other Characteristics “may” include:

Feeding problems in Babies
Seizures
Sensory Integration Issues
Congenital Heart Defects
Renal Malformations/Reflux
Hypospadias in Boys
Inguinal or Umbilical Hernias
GI Reflux
Scoliosis
Frequent Infections (Ear, Respiratory)
Sleep disorders
Glaucoma/Cataracts
Constipation
Behavioral Issues



Together We're Better

For over 25 years, our Network families have been raising awareness by exchanging information, discussing challenges and achievements, and getting moral support for their 9pminus family member. With the help of technological advancements in communication today, families all over the world are able to exchange information freely. Our Network has over 375 families, representing over 20 countries!

In addition, families are invited to attend the Network Family Reunions. These Reunions have become a vital part of our Network as many families have never met another 9pminus person. Reunions are a time of sharing, bonding and joy for all who attend!

“Coming together is a beginning; keeping together is progress; working together is success.”