

## Our Network Mission

- To promote the health and welfare of 9pminus families
- To advise and aid parents/guardians of challenges in raising an individual 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 9p minus chromosome disorders
- To encourage research related to the “p” arm of the 9<sup>th</sup> 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

### **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:**

*Chromosome 9pminus Network  
P.O. Box 15484*

*Baton Rouge, LA 70895  
Membership-services@9pminus.org  
(920) 931-2644*

#### Research Doctors:

*Dr. F. Sessions Cole, MD  
Dr. Marwan Shinawi, MD  
Dr. Dustin Baldrige, MD*



## **What in the World is 9p-?**

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P.O. Box 15484  
Baton Rouge, LA 70895*

**[www.9pminus.org](http://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 are 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: Kristi Klopfenstein, OH  
Vice President: Jill Holtzmann, MO  
Secretary: Terri Aguado, CA  
Treasurer: Chris Reid, LA  
Director: Jacqueline Bair, NY  
Director: Missy Reid, LA  
Director: Kyle Greig, Ontario, Canada  
Director: Cindy Kutz, LA  
Director: Bryan Kutz, LA  
Director: Brooke Strawn, MA  
Director: Lina Arenas, NY

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



### *Together We're Better*

For over 30 years, our Network families have been raising awareness by exchanging information, discussing challenges and achievements, and receiving 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 450 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.”

*Unknown*