Resources for Families

**The Chromosome 18 Registry and Research Society**
[chromosome18.org](http://chromosome18.org)
- The Chromosome 18 Condition Descriptions
  - Genetic Basis
  - 18p-
  - 18q-
  - Ring 18
  - Tetrasomy 18p
  - Trisomy 18
  - Pitt Hopkins syndrome
- Podcasts
  - What is a chromosome abnormality?
  - Why and how did this happen?
  - How is the chromosome analysis that diagnosed my child different from the research study molecular analysis?
  - What is the relative size of a chromosome to a gene to a base pair of DNA?
  - What is FISH analysis?
  - What is microarray analysis?
  - How does a Chromosome Abnormality cause disease?
  - What is the treatment potential for someone with a chromosome abnormality?
  - What is Pitt Hopkins syndrome: And how does it relate to 18q-?
  - What is our strategy for identifying treatments?
- **eNews**
  - 1 - 2 times per week, 1 per month on science
  - Past issues archived on website
- **Social Media**
  - Parents/ guardians – Ryver
  - Siblings – Facebook
  - Self-Advocates – Facebook
- **Live Broadcasts** – 18th of each month at 1800 hours US Central Time Zone

**The Chromosome 18 Clinical Research Center**
[http://pediatrics.uthscsa.edu/centers/Chromosome18/index.asp](http://pediatrics.uthscsa.edu/centers/Chromosome18/index.asp)
- **Management Guides**
  - 18p-
  - Distal 18q-
  - Proximal 18q-
  - Ring 18
  - Tetrasomy 18p
  - 2 video presentations for physicians; Scientific Background and Clinical Management Overview
- **Scientific publications available as PDFs (many with lay summaries)**
- **Ask the experts** - Hilla3@uthscsa.edu

**Others:**
- Wikipedia
- Genetic and Rare Diseases Information Center (GARD)
- Unique