A Word from MAX’s Parents

We found Share & Care after MAX was diagnosed at age 11. This network has helped our family learn more about CS and connect with other families around the world that have a child(ren) with this syndrome. All have helped us in our care of MAX throughout the years.

There is no cure for Cockayne syndrome.

What is Cockayne Syndrome (CS)?

Cockayne syndrome (CS) is inherited in an autosomal recessive pattern. In order for a child to be affected by CS, he or she must inherit a mutation (-) in the same CS gene from both parents. The parents and other “carriers” of a single CS gene mutation remain healthy.

Common CS Characteristics

Most common characteristics noted in CS are:

- Social, jovial personalities
- Sleeping with eyes open
- Premature aging
- Hearing loss
- Sensitivity to sunlight;
- Short stature (height 5\textsuperscript{th} percentile)
- Developmental & neurological delays
- Feeding problems
- Low body temperatures
- Unsteady gait
- Liver abnormalities: elevated liver enzymes
- Severe itchiness
- Tremors
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To find out more about our kids or to DONATE please log in to the Share & Care website.

www.cockaynesyndrome.org

FOR Designation & Dedication please type MAX

CockayneSyndrome.org
A Rare Genetic Disorder
Saturday, September 22, 2018
11am to 7pm
Deer Valley Golf Range
8015 Holcomb Bridge Road, Roswell, Georgia

EVERYONE is WELCOME!

Raffles (We are accepting items to raffle!)
Hit Range Balls (all balls purchased benefit the event)
Basic Golf Lessons 20 minutes for $20
Toddler Golf Area with Childcare available
and MORE . . .
Food for purchase | T-Shirts
Share a story about MAX | Learn about CS
Hug somebody! | Have fun!

ALL PROCEEDS FROM THIS EVENT
WILL GO TO SHARE & CARE COCKAYNE SYNDROME NETWORK!

For more information on the event, CS, or how you may get involved please contact us!

David or Lisa Sweeting: 678-772-4171 or 770-865-4839
dwsweeting@gmail.com
Seth or Jill Zimmerman: 678-230-4519
jillezimmerman@gmail.com

VOLUNTEERS are NEEDED! CALL Lisa for details!

Please consider coming TOGETHER with us as we celebrate a courageous young man!

Our Goals:

1) Raise a minimum of $10,000 for families of newly diagnosed children to travel to the Share & Care Annual International Family Medical Conference to meet the doctors who work with children who have Cockayne Syndrome. The syndrome is so rare that it is very difficult to find local doctors who understand the challenges of treating kids with Cockayne syndrome.

2) Take an opportunity to CELEBRATE MAX and the lives he has touched in his 20 years and the way he continues, every day, to touch people’s hearts.

Share & Care Cockayne Syndrome Network, Inc.
www.cockaynesyndrome.org

The Mission of Share & Care is
to help children with Cockayne syndrome and their families improve quality of life through support, education, and research. Share & Care Cockayne Syndrome Network focuses on their goal to help families obtain an earlier diagnosis and share information on medication and procedures that prove to be beneficial to children with Cockayne Syndrome.