

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.

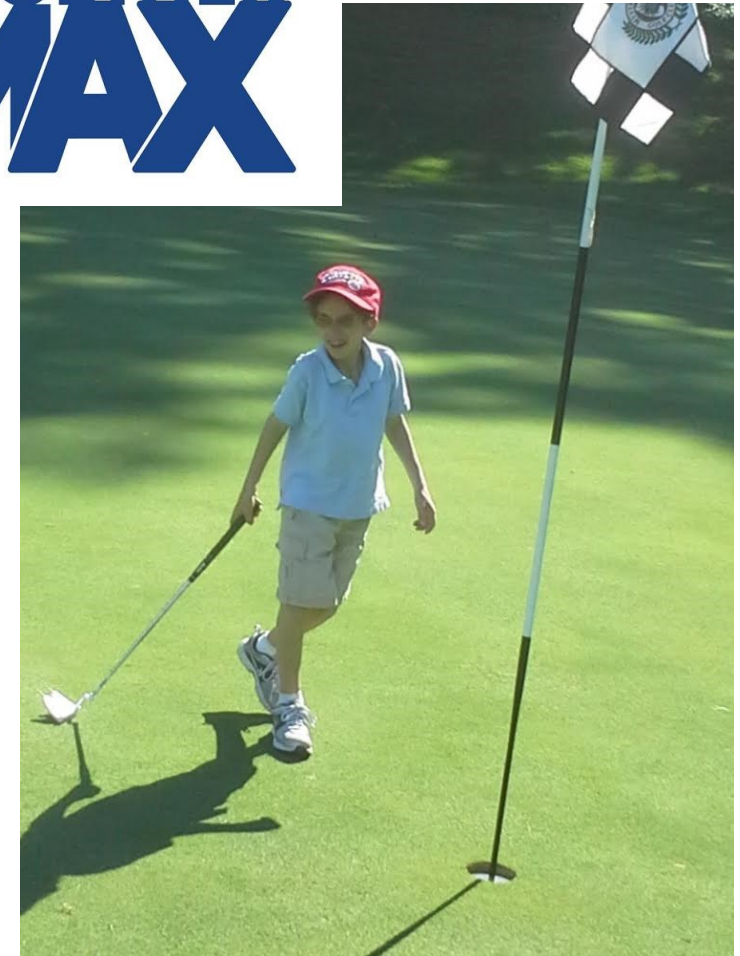
Common CS Characteristics

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 th percentile)
Developmental & neurological delays	Feeding problems
Low body temperatures	Unsteady gait
Liver abnormalities: elevated liver enzymes	Severe itchiness
	Tremors

TOGETHER for MAX

A Family Friendly Event



**Saturday, September 22, 2018
11am to 7pm**

**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.