Central Core Disease

Prepared for [client]

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March 23, 2014
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Disclaimer: *This report is offered as background information only. Joanne Zeis of Patient Pathfinders, the author of this report, does not offer medical advice, or diagnose or treat medical problems; she is neither trained nor qualified to offer these services. Your primary care physician and medical specialists are always the best resources for your specific situation. If you have questions about any of the information provided here, please direct them to the medical professionals handling your care. In addition, do not make any treatment decisions based on the information in this report, and ask your doctor(s) for guidance* ***before*** *adding or subtracting any treatments (including alternative treatments and any "natural" or herbal preparations).*

The author has tried to make this report as complete as possible, but it may not include all of the possible medical warnings, or diagnostic, symptomatic, or research/treatment-related options. A selection of specialists' names is provided for informational purposes only; no guarantees are made about their ability to provide satisfactory, complete and/or cost-effective medical care in your case.

Always speak with your healthcare professionals for the most complete information on this illness.

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OVERVIEW OF CENTRAL CORE DISEASE

Central core disease (CCD) is a form of muscular dystrophy. It falls under the category of congenital myopathies, which means – in most cases – it's an inherited condition. However, some people have developed CCD without any known family connections.

Central core disease is also known as:

- Central core myopathy
- Shy-Magee syndrome (after the people who originally researched it in 1956)
- CCD or CCO
- Muscle core disease

From the NIH Genetics Home Reference guide and from NORD, the National Organization for Rare Disorders (http://ghr.nlm.nih.gov/condition/central-core-disease and http://www.rarediseases.org/rare-disease-information/rare-diseases/byID/148/printFullReport):

> *Central core disease is a disorder that affects muscles used for movement (skeletal muscles). This condition causes muscle weakness that ranges from almost unnoticeable to very severe. The specific symptoms and their severity may vary greatly from case to case. Some individuals may develop very mild muscle disease that may go unnoticed; others may develop serious muscle disease that can cause serious breathing (respiratory) difficulties. In most cases, muscle weakness in CCD is not progressive or only progresses very slowly.*
>
> *Most people with central core disease experience persistent, mild muscle weakness. This weakness affects the muscles near the center of the body (proximal muscles), particularly muscles in the upper legs and hips.*
>
> *Central core disease is also associated with skeletal abnormalities such as abnormal curvature of the spine (scoliosis), hip dislocation, and joint deformities called contractures that restrict the movement of certain joints. The Achilles tendon is the most common site for contracture. Additional skeletal symptoms may occur, including front-to-back curvature of the spine (kyphosis), dislocation of the kneecap (patella), clubfoot (talipes equinovarus), flattening of the arch of the foot (flatfoot or pes panus), and an abnormally high arch of the foot (pes cavus). In some cases, muscle cramps or stiffness may occur, especially upon exertion.*

Certain facial muscles may be affected in individuals with CCD. In rare cases, individuals may develop wasting of facial muscles.

Central core disease gets its name from disorganized areas called cores, which are found in the center of muscle fibers in many affected individuals. It occurs in approximately 6 out of every 100,000 live births.

Considering the small risk of respiratory impairment, [we] advocate regular monitoring of respiratory capacity and annual overnight oxygen saturation studies if forced vital capacity (FVC) is less than 60% of the expected value, and more frequently if FVC is less than 40%. (From http://www.ojrd.com/content/pdf/1750-1172-2-25.pdf)

More information on respiratory involvement in CCD
(from http://www.ncbi.nlm.nih.gov/books/NBK1391/):

Pulmonary function testing [is recommended] in most patients, especially those with scoliosis, hypotonia [low muscle tone/reduced muscle strength], signs of respiratory distress, and/or history of recurrent chest infections. History should be taken for symptoms of nocturnal hypoxia [inadequate oxygen supply], including early morning headaches, daytime drowsiness, loss of appetite, and deteriorating school performance.

Treatment depends on the severity of symptoms, but mainly consists of supportive measures and rehabilitation that address the following problems:

- *Hypotonia and weakness. Patients may benefit from physical therapy. Interventions may include stretching programs and mild to moderate low-impact exercise; activities should be balanced in such a way that exhaustion is avoided.*
- *Routine assessment of respiratory parameters such as respiratory rate, peak expiratory flow rate (PEFR), forced vital capacity (FVC), and forced expiratory volume in one second (FEV1)*
- *Sleep studies, especially when patients show signs of nocturnal hypoxia*

Here is a 5-page, patient-friendly PDF of information on central core disease, from the Muscular Dystrophy Campaign in the UK:
http://www.muscular-dystrophy.org/assets/0001/6441/Central_Core_Disease.pdf

IMPORTANT WARNING!

Wear a medical alert bracelet, in case you are ever in an accident and unable to provide the following information:

According to the NIH Genetics Home Reference guide, *"People with central core disease have an increased risk of developing a severe reaction to certain drugs used during surgery and other invasive procedures. This reaction is called* ***malignant hyperthermia****, which can be a life-threatening condition."*

Two possible sources of medical alert bracelets are http://www.medicalert.org/ and http://www.americanmedical-id.com/

More information on malignant hyperthermia is found below.

Malignant hyperthermia (from http://quest.mda.org/print/14996):

Malignant hyperthermia is a reaction to certain anesthetics that leads to uncontrolled muscle contractions, accelerated metabolism, high fever, and all too often, if not treated, death. ***MH reactions don't always occur with the first exposure to inhaled anesthesia, so one event-free surgery is no proof that one does not have MH susceptibility.***

According to the Malignant Hyperthermia Association of the United States, the inhalation anesthetics that can trigger MH include sevoflurane, desflurane, isoflurane, halothane, enflurane and methoxyflurane. In addition, the muscle relaxant known as succinylcholine (brand name Anectine), a "depolarizing" relaxant often used with anesthesia, can also trigger the response.

MHAUS lists as safe for people with MH susceptibility (MHS) all local anesthetics, as well as the anesthetics and pain relievers nitrous oxide, barbiturates, narcotics, propofol, benzodiazepines, ketamine and etomidate. It lists the "nondepolarizing" muscle relaxants pancuronium, cisatracurium, atracurium, mivacurium, vecuronium and rocuronium as safe for use in people with MHS.

[According to http://www.globalrph.com/dantrolene_dilution.htm, dantrolene may be used to treat (and possibly prevent) a malignant hyperthermia crisis, pre- and post-operatively.]

Surgery can be safely performed on people with MHS, but it's important that the surgical team avoid the triggering agents and use the safe agents.

Family members who seem unaffected by CCD could be MH-susceptible and should assume they are until proven otherwise by a muscle biopsy or genetic test.

HOSPITALS / CLINICS / SPECIALISTS FOR TREATMENT OF CCD

There is no dedicated clinic or treatment center for CCD, either in the U.S. or abroad. However, neuromuscular departments or MDA clinics within larger medical centers are often well qualified to treat people with this illness.

Here is a selection of possible treatment locations / specialists.

The first neurologist is the only one I could find in your area (outside of the University of Pittsburgh) who specifically works with people who have neuromuscular disease.

- **Dr. William S. Musser, MD**
  Neurologist with dual private practice -- neurology and psychiatry
  Subspecialty interest in neuromuscular disease and movement disorders
  5171 Liberty Avenue
  Pittsburgh, PA 15224
  412-683-2414
  http://drmusser.net/
  He's received high grades from patients on healthgrades.com, but I'm never sure whether ratings have been planted on these sites. It's a good sign, though, that there are 13 reviews, all positive.
  http://www.healthgrades.com/physician/dr-william-musser-36524/patient-ratings#TopOfMain

- **Neuromuscular Diseases Section at Univ of Pennsylvania Health System (Philadelphia):**

  Mark J. Brown, MD, Hospital of the University of Pennsylvania, Philadelphia
  Dir of Neuromuscular Diseases
  Recognized by *Best Doctors in America* every year from 2003-2012
  800-789-7366
  http://www.pennmedicine.org/Provider-Search/Results.aspx?pid=896

  Sami L. Khella, MD
  Chief, Dept of Neurology, Penn Presbyterian Med Center
  Additional certification in neuromuscular disease
  800-789-7366
  http://www.pennmedicine.org/Provider-Search/Results.aspx?pid=1289

Unfortunately, everyone else beyond this point is outside of PA, but at least they're still in the middle/eastern U.S.

- **Washington University Neuroscience Center**

  Dr. Alan Pestronk (was mentioned in an article on a CCD patient; see pg. 14)
  Neuroscience Center, Center for Advanced Medicine
  4921 Parkview Place, St. Louis, MO 63110
  Phone: 314-362-6981
  Fax: 314-362-3752

- **Neuromuscular Medicine of Delaware**

  Dr. Enrica Arnaudo
  Neuroscience & Surgery Institute of Delaware
  774 Christiana Road, Suite 106
  Newark DE 19713
  Phone: 302-731-4663
  Fax: 302-731-2601
  http://www.neuromuscularmedicine.com/index.html

  A lot of the focus here seems to be on diagnosis, but they also do treatment. Dr. Arnaudo has also gotten good scores on healthgrades: http://www.healthgrades.com/physician/dr-enrica-arnaudo-2q5rx/patient-ratings#TopOfMain

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This next option (University of Rochester Medical Center) is included because one of the most-frequently-published researchers on CCD in the US is Robert T. Dirksen, and he's been doing research at University of Rochester for at least 20 years (although not all of it is on CCD). He doesn't do patient care, just research, but it's probably a good sign that he's still there, plugging away. The two doctors I've listed below from the Neuromuscular Disease Unit also seem pretty committed to experimental options for treatment, so you might find that interesting.

- **University of Rochester (NY) Medical Center, Neuromuscular Disease Unit**
  http://www.urmc.rochester.edu/neurology/units/neuromuscular-disease-unit.cfm

Robert C. Griggs, MD
University of Rochester Medical Center
School of Medicine and Dentistry
601 Elmwood Ave, Box CU 420669
Rochester, NY 14642
Appointment: (585) 275-8762
Dr. Griggs is an internist/neurologist specializing in neuromuscular diseases with ***a focus on experimental therapeutics****. He has directed an NIH-funded training program in the Experimental Therapeutics of Neurological Disease since 1989.*
Bio: http://www.urmc.rochester.edu/people/20623081-robert-c-griggs

Chad R. Heatwole, MD
University of Rochester Medical Center
School of Medicine and Dentistry
601 Elmwood Ave, Box CU 420669
Rochester, NY 14642
Appointment: (585) 275-8762
Dr. Heatwole's research has led to the development of an international network dedicated to improving the quality-of-life of neuromuscular patients through patient-centered clinical research. His primary professional interests include providing optimal care to patients with neuromuscular disorders, performing electrodiagnostic studies, training medical personnel, evaluating novel experimental therapeutics for neurological diseases though clinical trials, and developing an improved infrastructure to utilize disease-specific, patient-relevant endpoint measures for use in clinical trials and patient monitoring.
Bio: http://www.urmc.rochester.edu/people/21937422-chad-r-heatwole

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- **Neuromuscular Center at Cleveland Clinic, OH**

  Neuromuscular Center home page:
  http://my.clevelandclinic.org/neurological_institute/neuromuscular-center/default.aspx
  Appointments:
  http://my.clevelandclinic.org/neurological_institute/neuromuscular-center/appointments.aspx

  Most doctors in this clinic treat various forms of muscular dystrophy, so it may not matter which one you see.

- **Neuromuscular Center at Case Western University Hospitals**
  Cleveland, OH
  Brochure: http://www.uhhospitals.org/services/neurology-and-neurosurgery/institute/our-centers/neuromuscular/~/media/UH/documents/services/neuromuscular-center.pdf

  Gerald Grossman, MD
  Specializes in neuromuscular disorders, myopathies
  University Hospital Case Medical Center (Case Western University)
  Dept of Neurology, 11100 Euclid Ave
  Cleveland, OH
  http://www.uhhospitals.org/find-a-doctor/grossman-gerald-530
  216-844-3192

  Barbara Shapiro, MD, PhD
  Specializes in metabolic and muscular dystrophy, neuromuscular disorders
  University Hospital Case Medical Center (Case Western University)
  Dept of Neurology
  11100 Euclid Ave
  Cleveland, OH
  http://www.uhhospitals.org/find-a-doctor/shapiro-barbara-3588
  216-844-7768

- **Boston Area Hospitals:**

  Tufts Medical Center, 800 Washington Street, Boston, MA 02111
  Jeffrey M. Chavin, MD, Director of Neuromuscular Disorders Program
  "Voted by colleagues as one of Boston Magazine's top doctors in 2011 and 2012." 617-636-4948
  https://www.tuftsmedicalcenter.org/PhysicianDirectory/Jeffrey-Chavin.aspx?dpt=d0c40162-65b4-4924-b110-12374fd7acd9

  Brigham and Women's Hospital, 75 Francis Street, Boston, MA 02115
  Department of Neurology, Neuromuscular Service 617-732-8046
  http://www.brighamandwomens.org/Departments_and_Services/neurology/services/neuromuscular/default.aspx

- **Mass General Hospital**, 165 Cambridge Street, Boston, MA 02114
  Merit Cudkowicz, MD, Chief, Neurology Service
  (She also runs the MDA/ALS Center at MGH)
  Outpatient Adult Neuromuscular Clinic 617-643-2085
  http://www.massgeneral.org/neurology/services/treatmentprograms.aspx?id=1374

The Muscular Dystrophy Association also maintains a listing of MDA/ALS Research and Clinical Centers across the US. The list is available here:
http://mda.org/services/your-mda-clinic/als-centers

World experts in core myopathy research, gathered at the 150th ENMC International Workshop in Core Myopathies (2007), The Netherlands:

Robert Dirksen (University of Rochester Medical Center, USA)
https://www.urmc.rochester.edu/people/20383541-robert-t-dirksen
Brigitte Estournet-Mathiaud (Garches, France)
Ana Ferreiro (Paris, France)
Pascale Guicheney (Paris, France)
Susan L. Hamilton (Baylor College of Medicine, Houston, USA)
https://www.bcm.edu/education/programs/tbmm/?pmid=6829
Heinz Jungbluth (London, UK)
Isabelle Marty (Grenoble, France)
Gerhard Meissner (UNC School of Medicine, Chapel Hill, North Carolina, USA)
Nicole Monnier (Grenoble, France)
Francesco Muntoni (London, UK)
Ros Quinlivan (Oswestry, UK)
Caroline Sewry (London & Oswestry, UK)
Volker Straub (Newcastle, UK)
Susan Treves (Basel, Switzerland)
Thomas Voit (Paris, France)
Francesco Zorzato (Ferrara, Italy)

TREATMENT OF CENTRAL CORE DISEASE

Drug treatment

Central core disease is unusual among the myopathies in having a treatment that has been tried (successfully) in a small selection of patients in 2004 and 2010. Albuterol / salbutamol have been shown to help with muscle mass and strength of **some** patients with CCD. The first medical journal article below is accessible in full through the supplied link. The second article has been attached to the email that delivered this report to you:

- **Successful use of albuterol in a patient with central core disease and mitochondrial dysfunction**.
  http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3757256/pdf/10545_2010_Article_9085.pdf
  Schreuder LT, Nijhuis-van der Sanden MW, de Hair A, Peters G, Wortmann S, Bok LA, Morava E.
  J Inherit Metab Dis. 2010 Dec;33 Suppl 3:S205-9.
  doi: 10.1007/s10545-010-9085-7. Epub 2010 May 5.
  PubMed PMID: 20443062; PubMed Central PMCID: PMC3757256.

- **Pilot trial of salbutamol in central core and multi-minicore diseases.**
  http://www.ncbi.nlm.nih.gov/pubmed/15534757 (abstract only; see attachment to email for full article)
  Messina S, Hartley L, Main M, Kinali M, Jungbluth H, Muntoni F, Mercuri E.
  Neuropediatrics. 2004 Oct;35(5):262-6. PubMed PMID: 15534757.

Unfortunately, no other reports or trials have been published (or appear to be planned) on the use of this type of medication for CCD.

The future of treatment for CCD and other congenital myopathies probably centers on a mutation in the RYR1 gene that appears in up to 85% of CCD patients (http://www.ncbi.nlm.nih.gov/pubmed/24561095) More (exceptionally complicated) RYR1 gene information appears here: http://www.ncbi.nlm.nih.gov/pubmed/23919265

There is also evidence suggesting too much calcium in muscle cells contributes to CCD, but this should **not** be considered a recommendation to reduce your calcium intake!
http://quest.mda.org/article/coping-central-core-disease/#core_problem

An additional article on “CGRP, a vasodilator neuropeptide” has been attached to the email that delivered this report to you. I expect a physician will understand the implications (if any) of this vasodilator to treatment of CCD.

Complementary and alternative/natural treatments for CCD

Your current use of supplements appears to be in line with some of the recommendations from Dr. Andrew Weil for muscular dystrophy (http://www.drweil.com/drw/u/ART03137/Muscular-Dystrophy.html).

The Muscular Dystrophy Campaign in the UK has released a 4-page PDF on the use of a variety of alternative therapies. You can see it here: http://www.muscular-dystrophy.org/assets/0001/6337/Alternative_therapies.pdf

There is a site providing information on the treatment of muscular dystrophy with **Chinese herbal medicine** (verify safety of this approach and any ingredients with your healthcare providers **before** trying): http://www.taoiststudy.com/content/treating-progressive-muscular-dystrophies-md-herbal-remedy

A review article on the use of Qigong and Tai Chi for medical conditions, including muscular dystrophy:
A Comprehensive Review of Health Benefits of Qigong and Tai Chi
(Search within the article on the term "muscular dystrophy")
http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3085832/pdf/nihms281835.pdf
R Jahnke, OMD, L Larkey, PhD, C Rogers, J Etnier, PhD, and F Lin
Am J Health Promot. 2010 JUL-AUG; 24(6): e1–e25.
doi: 10.4278/ajhp.081013-LIT-248 PMCID: PMC3085832

Some control of pain and muscle spasms *may* be possible through hypnosis, muscle relaxation exercises, biofeedback or guided imagery; speak with your physician(s).

Finally, one family with a 9-year-old boy with CCD used mild electrical stimulation to force some of their son's weak muscles to contract and gradually grow stronger. I'm assuming this treatment was done under a doctor's supervision, but the article doesn't make it clear: http://static.mda.org/publications/Quest/q62ccd.html

Exercise for central core disease

There is no real consensus on the effect of exercise on CCD symptoms and its prognosis, although Dr. Susan Hamilton of Baylor College of Medicine in Houston had an interest in the relationship between CCD and exercise in 1999 (http://quest.mda.org/article/coping-central-core-disease).

According to the quest.mda.org article (above),

> *One thing that medical doctors, parents and researchers all agree on is that swimming seems to provide excellent non-weight-bearing exercise. Because so little is known about the effects of exercise in this disorder, people with CCD should exercise only under the supervision of a physician.*

According to an article on central core disease in the Orphanet Journal of Rare Diseases (2007) (http://www.ojrd.com/content/pdf/1750-1172-2-25.pdf)

> *Exercises promoting endurance and truncal stability, such as swimming and riding, may be particularly useful. Considering a tendency to exercise-induced myalgia [muscle pain] in CCD, exercises involving a high-resistance load have to be approached with caution and are probably not recommendable.* [sic]

From http://quest.mda.org/article/ccd-surprised-progression (an article about a CCD patient):

> *In January 2010, Doak visited the MDA clinic at Washington University in St. Louis and talked with neurologist **Alan Pestronk**, the clinic's director, and other professionals, including a physical therapist. She learned that what she had been told earlier by another doctor — that she could exercise as much as she wanted in whatever way she wanted — might not have been good advice.*
>
> *Much to her dismay, she learned that a combination of frequent stair climbing and regular use of an elliptical trainer, which she thought was building muscle, might actually have been destroying it. She's planning to work with the doctors and therapists at Washington University to modify her approach to exercise.*

From http://quest.mda.org/article/ccd-disease-many-faces:

> *Muscle cramps and pain are troublesome for many people, Susan Iannaccone says, and they can be prevented to some extent with stretching exercises. [Iannaccone is director of pediatric neurology and the MDA Clinic at Children's Medical Center in Dallas.] "Cramps are usually in the weight-bearing muscles,*

the calves and thighs," says Iannaccone, who recommends patients consult with a physical therapist before doing stretching at home.

Iannaccone also recommends consultations with a nutritionist to make sure patients are getting enough fluid, potassium and calcium, because a lack of any of these can contribute to cramping episodes.

For muscle pain, she recommends the anti-inflammatory medication ibuprofen, which can be purchased over the counter, and also encourages massage and warming of the muscles (such as in bathwater).

Although she doesn't have data to prove it, Iannaccone says she believes that, for people with CCD, "pain is not gain."

Physical therapy for central core disease

If you want to concentrate on PT, here are two possibilities. Both are certified in neurologic PT by the American Board of Physical Therapy Specialists (ABPTS) and have a specialty focus in PT for neuromuscular disorders:

- **Christopher Charles "Chris" Harrison, PT, NCS**
  200 Lothrop Street
  Pittsburgh, PA 15213
  (412) 692-4305 (Office)

- **Susan Balko-Perry, DPT (Doctor of PT), MS, NCS**
  Chatham College
  Woodland Road
  Pittsburgh, PA 15232
  She's an associate prof. at Chatham and it's not clear if she has a PT practice of her own, because no phone number was available. However, she might be able to recommend someone else if you contact her through email:
  perry@chatham.edu

Neuromuscular massage

- **Dena M. Vrabel, Massage Therapist**
  http://www.denavrabel.com/types_of_massage.html
  Office Hours by Appointment
  11:00 a.m. thru 8:00 p.m.
  Monday, Tuesday, Thursday and Friday
  Saturday available by special arrangement
  1384 Old Freeport Road, Ste 2
  Fox Chapel
  Pittsburgh, PA 15238
  412-963-6911 or email at dmvrabel@yahoo.com

- **Amy and Ian Green, Massage Therapists**
  http://pittsburghmassageworks.abmp.com/home
  Pittsburgh Massageworks
  1517 Hetzel St
  Pittsburgh, PA 15212
  412-626-2648
  Hours: http://pittsburghmassageworks.abmp.com/hours-and-scheduling

CLINICAL TRIALS FOR CENTRAL CORE DISEASE

There are no clinical trials right now that are investigating treatments for CCD. However, you may want to be involved in a genetics study:

Molecular and Genetic Studies of Congenital Myopathies

The Congenital Myopathy Research Program consists of a group of scientists and healthcare providers all working to better understand the congenital myopathies. We are taking two approaches to reach our research goals. The first involves identifying and describing new genes and proteins involved in the skeletal muscles that allow our bodies to move. Simultaneously, studies are underway to identify genetic changes (mutations) that cause human neuromuscular disease. Thus, our second approach is to identify mutations, learn how they are inherited in families, and understand how they lead to weakness in individuals with neuromuscular disease. These approaches allow correlation of our basic muscle biology findings with our studies on muscle tissue of affected individuals.

Our research would not be possible without the generous participation of individuals and families with congenital myopathies. Participation in our studies is free of charge. Travel to Boston is not required, and we welcome the participation of individuals from around the world.

We appreciate the participation of all individuals with a congenital myopathy, as well as their first-degree relatives. Participants with a congenital myopathy are asked to donate medical records, a blood or saliva sample, and a muscle tissue sample (if available). Participating relatives are asked to donate a blood sample. The blood/saliva sample is used to acquire DNA (genetic material) which can be used to identify genetic changes and to study how a disease is inherited in a family. The medical records are employed to understand a participant's symptoms. The muscle tissue is used to better understand the disease at the muscular level by studying the gene expression and protein levels in individuals with congenital myopathies.

For more information, visit the Laboratory Website at www.childrenshospital.org/research/beggs

Please refer to this study by its ClinicalTrials.gov identifier: NCT00272883
Contact: Lindsay Swanson, M.S. C.G.C. (617) 919-2169
lswanson@enders.tch.harvard.edu

ONLINE SUPPORT FOR PEOPLE WITH CENTRAL CORE DISEASE

As you might expect, there aren't many available online support groups for people with CCD, but **support groups are often your best source of recommendations for specialists in your area or geographic region.**

1. **A "closed" international Facebook group for Central Core Disease & Minicore, with 241 members:**
   (you need to contact the group's administrator to join):
   https://www.facebook.com/groups/243087794204/

2. **Central Core Disease Support System (on Yahoo) with 136 members**
   https://groups.yahoo.com/neo/groups/centralcoredisease/info

3. **A new CCD support forum that appears to have been created in February 2014**
   http://www.centralcoredisease.com/viewforum.php?f=1

If you'd like to further the cause of CCD by encouraging future research, the site **PatientsLikeMe** is looking for people with CCD to sign up and share information about their health and medical histories. PatientsLikeMe contracts with pharmaceutical companies and researchers who are looking for new drug/treatment development possibilities. Only one other CCD patient is currently enrolled:
http://www.patientslikeme.com/conditions/2034/overview