



Families Together, Inc.

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Connections

Winter 2018

A quarterly publication from Families Together, Inc., the Parent Training and Information and Health Information Center for the state of Kansas

Thank you to Sean Tyree for sharing your story. Families Together is honored to encourage families like yours to become educated and empowered as advocates for yourselves and others with disabilities.



Hello, my name is Sean Tyree. I am a 15 year old sophomore high school student with a rare disease called Charcot Marie Tooth, CMT for short. CMT is a genetically inherited disease that affects your neuromuscular system. The disease destroys the myelin sheath of your nerves which makes your nerves not fire correctly and when that happens you get pain and long term loss of certain muscle functions. My disease affects muscle wasting from my elbows to my hands and my knees to my feet. My disease is progressively degenerative, meaning, it doesn't get better, and it only gets worse with time. We as patients can try our best to try and slow the progression, but

that is not always possible when this disease makes you tired and can affect your hearing, respiratory system, spine (scoliosis), etc. Thanks to Families Together, my family was able to secure a travel scholarship to attend a Hereditary Neuropathy Foundation (HNF) conference in Boston, MA in early November - <https://www.hnf-cure.org/>. Being able to attend this conference allowed me to network with other individuals who also have my disease and make lifelong friendships. Having these people available to me, they can give me advice on all kinds of things to do to help me maintain my health, body and strength: OT, PT, surgeries, adaptive equipment, etc. Additionally, hearing the doctors talk at the conference gave me and my family HOPE...HOPE that even though there may not be a cure, but at least a drug that could not only slow the progression but maybe stop it all together. I am so excited about this. The founder of HNF, Allison Moore, has asked me to be a youth advocate for HNF as well and help with coordinating a conference in 2018 where the FDA will approve the drug that I am so excited about. Thank you Families Together for the scholarship; as you can see, the opportunity has given me and my family so many resources and hope to find a cure.



Beating the Winter Blues

By the time our newsletter arrives in your mailbox, the holidays are over and winter has arrived in full force. You are finding yourself struggling to complete even the simplest of tasks. Perhaps a case of the winter blues have hit you.

Many people suffer from "Seasonal Affective Disorder" or SAD. For people with SAD, the lack of natural light in the wintertime upsets the wake-sleep cycle and the release of serotonin, the brain's "feel-good" chemicals. SAD can be problematic for anyone but is more common in women, seniors, and caregivers. These tips can be helpful in beating the winter blues and can be enjoyed by everyone in the family.

1. **Go outside.** Even if it is cold, bundle yourself up and take a brief walk. Take your toddler in their stroller, or little ones in a wagon. Everybody's spirits can perk up when there is a change of scenery.
2. **Exercise.** Create an indoor exercise routine. Search for an app called "7 Minute Workout". There are many choices both free and paid. If you do not like the first one, try another. Use your smart phone to keep track of your activities. Health tracker come already installed on the iPhone and it is available as a free download on your Android. This app can keep track of your health data, activity,

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Winter Blues continued:

sleep patterns and more. Before beginning an exercise program, do consult your physician.

For more tips, you can download a tip sheet from Families Together, Inc. at <http://bit.ly/2D7tJzO>



Gracias a Sean Tyree por compartir tu historia. Families Unidas tiene el honor de alentar a las familias como la suya a que se eduquen y empoderen como defensores de sí mismos y de familias que tienen niños con discapacidades.

Hola mi nombre es Sean Tyree, tengo 15 años y soy estudiante de secundaria. Padesco de una rara enfermedad llamada Charcot Marie Tooth, (por sus siglas en Ingles) para abreviar es CMT. CMT es una enfermedad genetica que es heredada y afecta el sistema neuromuscular. Esta enfermedad destruye la capa de mielina de los nervios, lo que hace que los nervios no se proyecten correctamente y cuando eso sucede causa dolor y la perdida de ciertas funciones musculares a largo plazo. Mi enfermedad afecta el desgaste muscular desde los codos hasta las manos y las rodillas hasta los pies. Mi enfermedad es progresiva degenerativamente, es decir, no mejora y solo empeora con el tiempo. Sin embargo nosotros como pacientes podemos dar lo mejor de nosotros para tratar de retrasar la progresion pero eso no siempre es posible y menos cuando esta enfermedad te hace sentir cansado y afecta tu audicion, tu sistema respiratorio, tu columna vertebral(escoliosis)etc. Gracias a Fami-

lias Unidas mi familia pudo asegurar una beca para viajar y asistir a una conferencia de la fundacion Hereditaria de Neuropatia (HNF en sus siglas en Ingles) en Boston, MA a principios de Noviembre- <https://www.hnf-cure.org/>. El poder asistir a esta conferencia me permito establecer contactos con otras personas que padecen mi misma enfermedad y hacer amistades para toda la vida. Al tener a estas personas a mi disposicion que puedan darme consejos sobre todo tipo de cosas que me ayude a mantener mi salud, mi cuerpo y mi fortaleza. OT, PT, cirugias, equipos de adaptacion, etc. Adicionalmente escuchar al Doctor hablar en la conferencia me dio a mi y a mi familia ESPERANZA.... ESPERANZA que talvez no haya una cura pero al menos hay una droga que no solo podria atrazar la progresion si no que a lo mejor lo puede parar todo junto. Estoy muy emocionado por esto. La fundadora de HNF, Allison Moore, me a pedido que tambien sea defensora de la juventud de la HNF y ayudar a cordinar una conferencia en el 2018 en la que la FDA aprovara la droga de la cual estoy muy emocionad. Gracias a Familias Unidas por la beca. Como pueden ver esta oportunidad nos a dado a mi y a mi familia muchos recursos y esperanzas para encontrar la cura.



Did you know Families Together Inc. has 2 Facebook pages?

www.facebook.com/FamiliesTogetherInc

Or en Español

www.facebook.com/familiasunidaskansas/

ANNOUNCING ONLINE SUPPORT GROUPS ON FACEBOOK

Families Together, Inc. is proud to announce two online support groups on Facebook. If there is interest, we can create more groups. Our purpose is to create a safe space to talk about the challenges and rewards raising a child with special needs. Each group's name begins with "Parent Talk" because the group belongs to you—the parent. If you want more information, please contact one of our parent centers. Our phone numbers are on the back page. You may also email us at :

website@famiestogetherinc.org

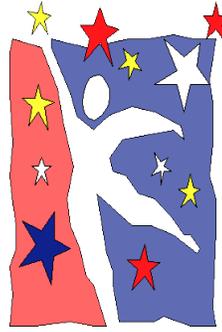
If you are the parent of a child on the autism spectrum, we would love to have you join us at www.facebook.com/groups/parenttalkautismsupportgroup/.



If you are the parent of a child with cerebral palsy, we would love to have you join us at www.facebook.com/groups/parenttalkcerebralpalsysupportgroup/.



What Exactly is a Free Appropriate Public Education?



On March 22, 2017 the U.S. Supreme Court issued a unanimous decision interpreting the definition of Free Appropriate Public Education (FAPE). The Court overturned the Tenth Circuit's decision that Endrew, a child with autism, was only entitled to an educational program calculated to provide "merely more than 'de minimis' educational benefit." The Court determined that "to meet its substantive obligation under the IDEA, a school must offer an IEP that is reasonably calculated to enable a child to make progress appropriate in light of the child's circumstances." The Court further emphasized the requirement "every child should have the chance to meet challenging objectives."

So, how can IEP teams "reasonably calculate" an IEP which enables a child to progress? The Office of Special Education Programs (OSEP) interprets this language as meaning school personnel will make decisions that are informed by their own expertise, the progress of the child, the child's potential for growth, and the views of the child's parents. Teams must consider how special education and related services have been provided in the past, including the effectiveness of specific instructional strategies, supports and services. The team must consider the child's previous rate of academic growth, whether the child is on track to achieve or exceed grade-level proficiency, any behaviors interfering with the child's progress, and additional information and input provided by the parent(s).

If you'd like more information about this decision, contact Families Together, Inc., search online for *Endrew F. v. Douglas County School District*, or use <http://bit.ly/2yScEq>



SAVE THE DATE

Families Together, Inc. will be hosting a night of fun, food and music on Saturday, April 21, 2018. Dueling Pianos will be providing the entertainment at Distillery 244 in Old Town, 244 N Mosley-Old Town, Wichita. Happy Hour will begin at 5:30 pm and the tickets will be \$50 per person. Tickets are available at Eventbrite using this shortcut: <http://bit.ly/2yZIO4a> Look for more information on our Facebook page and by email.

We still have a few spots for people who love to plan a party. For more information about the event or to volunteer to help, please call Randi at the Wichita office at 1.888.815.6364.

From the Director's Desk

Dear Parents and Appointed Education Advocates,

As we look forward to the New Year, we want to make sure that all families and education advocates continue to call Families Together with questions as they come up. Our staff is ready, willing and able to help problem-solve what might be your next steps in partnering with the schools, doctors or other professionals, or make some suggestions when there is a "sticky" situation.

Many parents have called over the years with the request for a Families Together staff member to attend an IEP meeting with them. Unfortunately, the answer has typically been "no". We simply do not have enough staff to accommodate that request. HOWEVER, we are creating a fund from donations and bequests to foundations to begin a pilot program to train parent-advocates to attend meetings with other families.

Your donation to Families Together's campaign will move this idea more quickly to fruition. Please pass on the link below to others who care about your child, maybe a grandparent, godparent, aunt or uncle? With your contribution, we hope 2018 will be the year Families Together can say, "Yes, we can attend your next IEP meeting."

<https://tinyurl.com/yda6vh8z>

May 2018 be the best year yet for the education and health of children with disabilities or special health care needs and their families in Kansas!

Connie

Families Make the Difference

Families Together, Inc. founded in 1982, serves as the Parent Training and Information Center and Family-to-Family Health Information Center for Kansas and provides opportunities for families to come together and meet other families who are navigating the special education and disability services maze. Each year, Families Together, Inc. provides, without fees, direct support to thousands of Kansas families. In addition, through workshops, conferences and partnerships with state, local and national organizations, Families Together provides training to nearly 4,000 families and professionals working with children and youth with disabilities and special health care needs.

Garden City Center 1-888-820-6364
 Topeka Center 1-800-264-6343
 Wichita Center 1-888-815-6364

gardencity@famielstogetherinc.org
topeka@famielstogetherinc.org
wichita@famielstogetherinc.org

<https://famielstogetherinc.org>

<i>Jan. 23, 2018</i>	<i>Education Advocate Training Kansas City, KS (Register Here)</i>	<i>1-800-264-6343</i>
<i>Jan. 26, 2018</i>	<i>Family Employment Awareness Training Part 1 Garden City (Spanish) (Register Here)</i>	<i>1-888-820-6364</i>
<i>Jan. 26, 2018</i>	<i>Family Employment Awareness Training Part 1 Garden City (English) (Register Here)</i>	<i>1-888-820-6364</i>
<i>Feb. 2, 2018</i>	<i>Together We Can Learn - Wichita Health/Education Statewide Conference (Register Here)</i>	<i>1-888-815-6364</i>
<i>Feb. 10, 2018</i>	<i>Family Employment Awareness Training Part 2 Garden City (Spanish) (Register Here)</i>	<i>1-888-820-6364</i>
<i>Feb. 10, 2018</i>	<i>Family Employment Awareness Training Part 2 Garden City (English) (Register Here)</i>	<i>1-888-820-6364</i>
<i>Feb. 20, 2018</i>	<i>Education Advocate Training Pittsburg, KS (Register Here)</i>	<i>1-800-264-6343</i>
<i>April 21, 2018</i>	<i>Dueling Pianos Benefit for Families Together, Inc. Wichita, KS (Register Here)</i>	<i>1-888-815-6364</i>
<i>April 21, 2018</i>	<i>Team Empowerment Conference "Get Pampered!" - Garden City (Message)</i>	<i>1-888-820-6364</i>

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Families Together, Inc.

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