



# S.C.A.N. & A.C.A.N.

Supporters of Children with Additional Needs and Additional Chairs for Additional Needs

October 2013



## S.C.A.N. Education & Activity Center

### Grand Opening, A Huge Success!

Our center is now up and running. The Grand Opening was a huge success with over 180 people coming through our doors that day. The kids loved Louie, from the Springfield Cardinals. Thanks Dr. Marla Smith for bringing him! They also loved Miss Leslie's music therapy.

Remember our Grand Opening Membership discount is still in effect until October 14; so get those memberships in today to take advantage of this discount.



"All children are special, ours just have additional needs"

### Upcoming Events

- October 5**-Soccer Camp 9-1 (October 12 rain date)
- October 11**-MPACT Training 6pm @ the center
- October 12**-Parent's Night Out
- October 19**-Believe in ME 5k for Down Syndrome Awareness
- October 26**-Sibling Support Group 10am @ the center
- October 27**-Gunther's Pumpkin Patch 2pm
- October 31**-Halloween Party at the Center 5-8pm

**Every Tuesday & Thursday-**  
Mommy & Me 9:30-10:30 @ the Center \$5 per session or free with membership

Be sure to check out our webpage [www.scankids.com](http://www.scankids.com) for more events and follow us on facebook activities as they become available.



### MOMMY & ME

Have you heard the news? S.C.A.N. now offers Mommy & ME classes!

We will have music, crafts and lots of fun for all children 5 & under who are not in kindergarten yet.

Classes are Tuesdays & Thursdays from 9:30-10:30.

These are free with a paid membership or \$5 per sessions.

## Raising Awareness! Focus on: Pitt Hopkins Syndrome



What is Pitt Hopkins syndrome?

Pitt Hopkins Syndrome (PHS) is a rare genetic disorder affecting a specific gene in chromosome 18, called TCF4. PHS is characterized by intellectual disability and developmental delay which range from moderate to

severe, possible breathing problems of episodic hyperventilation and/or breath-holding while awake (55%-60%), recurrent seizures/epilepsy (40%-50%), gastrointestinal issues, and distinctive facial features. Children with Pitt-Hopkins syndrome typically have a happy, excitable demeanor with frequent smiling and laughter. PHS was first described by D. Pitt and I. Hopkins in the Australian Pediatric Journal in 1978. The connection to TCF4 was not established until 2007 when it was found to play an essential role in the development of the nervous system and the brain. Any functional deficiency of TCF4 greatly affects how a child develops over time.

Overall prevalence of PHS is unknown, but estimated at between 1 in 34,000 and 1 in 41,000. PHS occurs in both males and females and is not limited to a specific ethnic background.

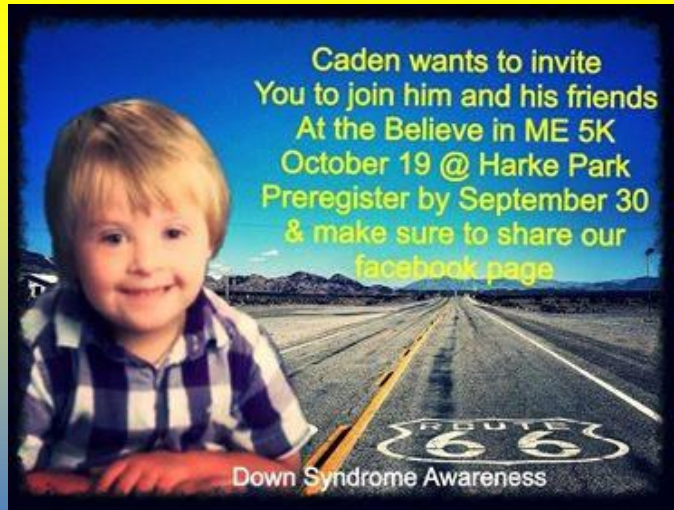
### A Changing Perspective

In the recent past, it was believed that all children affected by PHS would suffer from severe to profound overall disability, unable to walk, speak, or relate to others. All hope was taken away from parents who received a PHS diagnosis for their children. It's amazing how this perspective has changed over the last few years. We have found through recent research efforts PHS children are creative, vibrant, and joyful people continuing to learn over time, and who seem to bring happiness to everyone who knows them.

For more detailed information, please see the National Institutes of Health Gene Reviews article on Pitt Hopkins Syndrome: <http://www.ncbi.nlm.nih.gov/books/NBK100240>



JohnJohn, is often seen as our profile for ACAN & has Pitt Hopkins Syndrome



Check out their facebook page or email [believeinme5k@yahoo.com](mailto:believeinme5k@yahoo.com)

## Parents Night Out

S.C.A.N. will be providing it's very first Parents Night Out. This will be October 12 from 6-9 pm.

We will be showing the movie Hotel Transylvania. We will have popcorn, pizza, drinks, games & crafts.

October is Down Syndrome Awareness Month so what better inspiration than our own Varonica in a cap and gown!



# SINCE WE LAST SENT A NEWSLETTER . . .



*As you can tell, even though we've been out of school and had a lack of newsletters, we've had a blast during the summer of 2013!*