

JOA's Happenings
Read all About it and Get Involved to Derail Duchenne

Blessings & Breakthroughs

October 12, 2012



We cannot believe it is OCTOBER and the last time we chatted was JULY! So much has been going on around here, all good stuff, but it has been impossible to sit down and connect with you guys! So here we are, we are already scheduling time with our friends for the end of NOVEMBER... eekk where did the year go – Christmas is right around the corner! Life baby.... It moves fast.

That brings me to our Christmas wish from last year... I am thinking I can talk about it now on JOA since it has been granted, installed and functioning!!! Last year on Majic 105.7 John Owen posted his "Holiday Wish" as the commercial said... "grant your wish on" It was pretty simple, he wished for an elevator in our home so he could share our entire house with

us. Well, we did not hear back from the radio station..... but God certainly heard us!

Our Marathon Dad, Joe Vasil read the post and in one short week he assembled a huge group of



our family and St. Albert the Great family who set out to grant Owen's wish. On Christmas Eve 2011 at least 10 cars pulled in our driveway, this amazing group of people got out and started singing "Hark the Harold Angels Sing" until we came out – then handed Owen his Christmas Wish..... a Pledge to Build our Elevator! And they DID IT!

This photo of Joe and Owen was taken in August during the construction as Joe handed Owen 'the check'. I really have not allowed myself to wrap my brain around this... finally starting now and each time I do.... I cry pure tears of JOY. It is unreal as to what our Community has done for our son, what our school family has done for our son and what our family has done for our son.... It is like Christmas every day as Owen rides up and down between floors.....So if you are reading this and you were part of LIFT THEM UP - please send your family photo our way so we can see your beautiful faces every day we Lift him up!!!

**THANK YOU THANK YOU !!!!! Check out his first ride~
....How do we follow that? How about with our *MARATHON MOM'S* Elsa**



Kilbane and Irene Fitzgerald, both running to derail Duchenne. Elsa just starting her marathon bug and Irene ending her Marathon career of 25 yrs. Please visit [Marathon runners](#) to learn about these awesome moms that keep our Moving Spirit alive and used all their might to Derail Duchenne... They are also our newest Heroes... please check all our [Heroes](#) out also!



A Great Fall Tradition ~ YUMMO

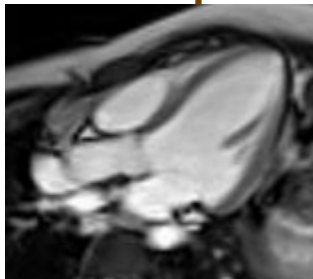
We are so excited about Country Stove, Patio & Spa's Chili Cook off on 10/27/12. Gloria Federico and her staff have dedicated their first cook off to JOA and want to help us Derail Duchenne! [Click here](#) to read more and sign up (scroll to middle). Tony and I will be competing in the cook off and we encourage you to come out and support us! 12 to 3 pm on Saturday 10/27 – what a great way to spend a Fall day! Thank you so much Gloria for your support.

Ladies that love to shop....

Local or not – you can participate in this cool fundraiser! Our friend Alicia Brown is a Scentsy and Grace Adale consultant and has opened her on line store to JOA! You guys out there – shop here for your sweeties for Christmas..... right – easy peasy! Ladies please check out these great sites, you will find gifts for everyone and something special for yourself! 100% of the profits will go to JOA! Thank you Alicia! Click it... [Scentsy Grace Adele](#)

Taking LEGO to HEART

I love this picture... it is Owen's **Healthy Heart**..beating!!!! We



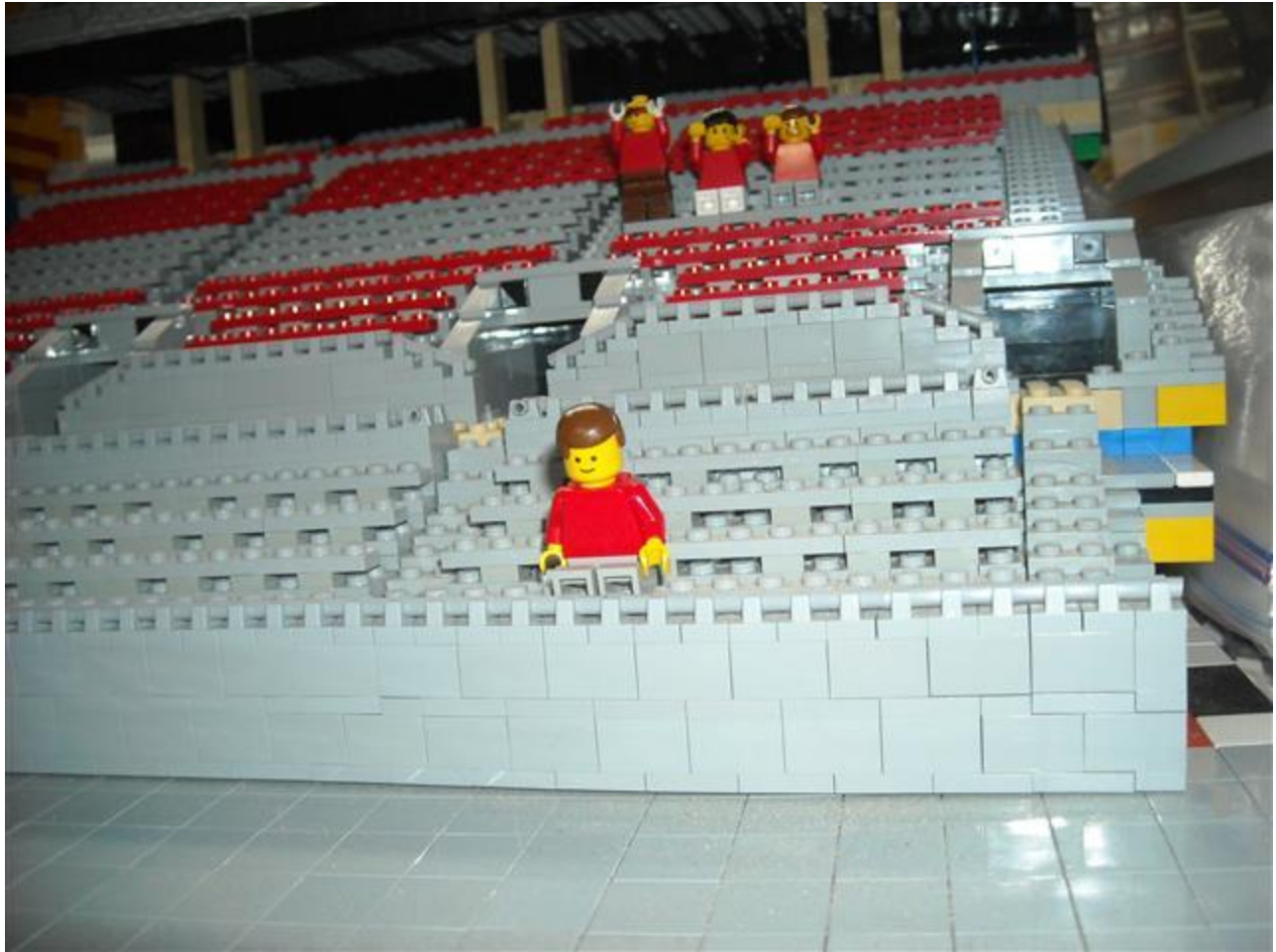
visited OSU last month to discuss a heart study and the result was this beautiful image of his perfect heart! We also got to meet a very cool team of doctors at OSU that are working

diligently to keep this heart and all Duchenne hearts beautiful through cardiac research.

Owen was treated to a private tour of Dr. Janssen's LEGO world... if you know Owen ~ you know he absolutely adored this experience!



Dr. Janssen is an amazing Lego Designer in his spare time. He built the entire OSU Stadium out of Lego's ([check it out here](#)) and has turned that passion into a fundraising project. For a donation of



\$20 or more, he will put a little LEGO person in the OSU stadium in your name (that is Owen in the front row at the Horseshoe). The goal is to fill the stadium.... Yep that means tons of needed \$ for our precious little hearts...Please donate to Heart/Muscular Degenerative Diseases Research Fund (313809) click [here for the link](#). Thank you to



Dr. Paul

Janssen; Associate Professor of Physiology and Cell Biology, Associate Professor of Internal Medicine, Cardiology at The Ohio State University and his team for doing what they do every day..... derail duchenne!

Welcome new board members!

We are thrilled to welcome Jennifer Briese, Ashley Gay and Amy Schultz as JOA Board members, please check them out on our [JOA Board page](#). We are honored to have their service.

Well let's end with the best news.... **Shall we?**

Eteplirsen is derailing Duchenne

Just out last week was the news about [Sarepta Therapeutics](#) (bioresearch firm) 48 week human trial results for a drug designed to 'skip' exons and the results were **extremely encouraging!** What does all this mean? This company (and one other, GSK) have been working diligently to develop a drug to slow the progression of this muscle killer, this study has shown through 12 boys that the drug is working!

Although it is fantastic news, the actual FDA approval and getting that drug into our Duchenne boys that can benefit (13% of our DMD boys, Owen included) will take some time, of course **time that none of our guys have**. We have been watching this drug for five years (since Owen was diagnosed) and have waited painfully long to see it finally get into boys in the U.S. and get these result.

So pray for **speed**, pray that the **FDA doesn't hold this up**, and pray that if this is to be, then let it be and let it be RIGHT NOW! We are very excited but also not counting on this to be the answer.... Not yet anyway.

Wow... so much in this update because as you know **this train is never stopping** until we derail this darn thing!

All the boys are doing so well and we



have thoroughly enjoyed the start of Fall, which was kicked off by our nephew Weston's wedding to his beautiful bride Lauren.

School is great for all 3 and can't believe that Wade is now in school with his brothers in Kindergarten ~ I had tears in my eyes this morning as we



prepared his "All about Me" photos – he has grown so fast and still continues to be the one that always makes us laugh.

Rutger is enjoying fifth grade a



nd is gearing up for hunting & wrestling season. He had another banner Fishing trip with Tony in Sept - check out his catch! We are so proud of the young man he is becoming! He continues to be such a responsible big brother, what a joy he is.

Owen of course is loving his elevator and doing very well in school. His heart update was a great relief and every day we are thrilled to pieces that we have our beautiful three boys to cherish....



So go on now, shut this off and go give the ones you love a great big hug!!

We will catch up again soon until then ~much love

Tony, Jen, Rutger, John Owen and Wade xoxox

~~~~~

**PICNIC IN THE PARK**

7/11/12

I don't think I have shared with you, yet, the pit in my sto



mach. I felt it for the first time at one of our recent gatherings. I know this is supposed to be a cheerful update about all the great things happening in a few days ~ but I have been overwhelmed lately by the brutal reality of Duchenne & I guess it is appropriate to share it now ~ now because it is more important than ever that you realize what your attendance at our fifth annual **Picnic in the Park** means...we gotta derail this thing....

The 'pit' occurred the first time I viewed a summer 2011 photo of John Owen shared with me at our recent bonfire. Seeing him walking, standing, playing at that bonfire.... Instantly my heart said that 'was the past'.....the *way* past &

he will *never, ever* be able to do that again. I looked up and over at him as he was again, at a bonfire, still happy, still playing, still with friends, but in his chair. I did not realize until that moment that his chair would be in every picture of him going forward, not just temporarily, but for the rest of his life. I would never again view a picture of our happy, carefree child: standing, walking, playing with his friends...

In a very few short days we are going to **CELEBRATE his life & the life of all kids** that need us so desperately to **rejoice in today!** So please take this update if as nothing else but a way to give to all these amazing boys because they are just like your son, actually, they are exactly like your son/child/brother/cousin/friend/neighbor.....They just need **you** to derail Duchenne, so whatcha waiting for.....?????..... bring it on BABY!!!! Hold on to your seats... there is A LOT going on here at JOA in JULY!!! It is not too late to volunteer so please do by [clicking it!](#)

Party in the Park is Friday Night ~7.27.12 ~ \$



# J.O.A.



## 2<sup>ND</sup> ANNUAL TEXAS HOLD'EM NO-LIMIT TOURNAMENT

### \$75 TO ENTER

\$25 ADD-ON & RE-BUY IN FIRST HOUR

POP ♦ BEER ♦ PIZZA ♦ SIDE GAMES ♦ RAFFLES

Must be at least 21 years old to play

Friday July 27<sup>th</sup> at German Central  
Registration Starts at 6:00 ♦ Cards Dealt at 7:00  
Register at [www.JOAinc.org](http://www.JOAinc.org) by July 25<sup>th</sup>  
for \$250 extra chips!\*

Questions? Call Guy at 440-390-0677

**ALL PROCEEDS GO TOWARDS HELPING TO PUT A "BAD BEAT" ON DUCHENNE MD**

German Central 7863 York Road, Cleveland, OH [www.JOAinc.org](http://www.JOAinc.org)

\* = Assumes 125 entries \*\*=Otherwise players start with \$1500 in chips

donation at the door with ID check ~ Featuring the Ribs, Beer and Bands:  
~**Liverpool Lads**

**~Masters of Disaster**

**~Squish the Band**

Kick it off at 5:30 pm & wrap up at 11.

**Texas Hold em** is back & starts at 6 pm \$75 to play. This is a 21 & over kinda crowd complete with awesome German Beer & Famous Dave's Ribs.

Pre-register for Texas Hold em at

<http://www.joainc.org/Pages/JOATexasHoldEm.aspx>

Raffle tickets for our ever popular [JOA baskets](#) will be sold & 7-11 Dice Game will hit from 7 pm to 9 pm your chance to win big with this high-energy game with great prizes.



**Picnic in the Park kicks off Saturday 7.28 at 5 pm!** This is a FREE Family centered event. We are so excited to welcome back The Polka Pirates & Jabez. New this year, center stage is **The Burning River Ramblers**. Kids games, thousands of dollars in raffle items, awesome affordable food & great entertainment.

If you have planned your family vacation around these dates, don't worry you can still get in the game ~ consider purchasing Basket tickets in our Pre-Sale Booklet = \$20 for 15 Epic, 3 11<sup>th</sup> Hour, 1 eXtreme. They will be sold

# JOA Picnic in the Park

Annual Weekend of Games, Live Bands, Raffles,  
Texas Hold'em Tournament

**German Central Park, 7863 York Road, Parma, OH 44130 440.230.1555**

★★★★★★★★★★★★★★★★joainc.org★★★★★★★★★★★★★★★★

## Party in the Park

5:00pm—11:00pm

**\$75 to Enter \$25 add on & Re-buy in First Hour \$5,000\* in prize money *Must be 21 or older* Registration starts at 6 Cards deal at 7 Register & pay by July 25 for extra \$250 in chips**

## Picnic in the Park

Games for adults and kids,  
Hole in one  
contest , plenty of kids games  
and prizes.

individually at the picnic at face value.... Epic \$1.00 11<sup>th</sup> Hour \$1.00 eXtreme \$5.00. Or if you would like to help us pre sell tickets let me know via [jen@joainc.org](mailto:jen@joainc.org) ~ you DO NOT have to be present to win.

Here is the scoop on the raffle baskets ([click here](#) for the list)

**Epic** ~ 50 numbered basket \$1.00 Blue Tickets ~ put your ticket in the corresponding bag in front of the basket or circle the # on your ticket and we will place for you ~ Drawings held throughout night 7.28.12

**11th Hour** ~ \$1.00 White Tickets~ Put your ticket in the drum, if your ticket is pulled grab whatever basket you want! Drawings held throughout night 7.28.12

**eXtreme** ~ \$5.00 Yellow Ticket ~ select one of the high priced items, put ticket in the corresponding box or circle the # on your ticket and we will place for you drawing at 9:30 pm 7.28.12

7-11 ~ Dice game to buy tickets you have to play \$5 = 1 ticket & 2 minutes rolling dice each time you hit a 7 or 11 you get a ticket ~ raffle picked at 9:30 Friday night & Saturday night ~ you do have to be there to play ~ it is so much fun.

**Hole in One** golf contest is back ~ yee haw~~ 3 top prizes awarded, top golfer takes home the top prize at 8:30 pm.

Of course we are thrilled to welcome back those that are truly dedicated to John Owen through their generous handcrafted spirit:

Falkinburg Decoy's 'Owen's Choice' *Cardinal* (Silent Auction, last year's piece went for \$1,000 Brad Falkinburg is AMAZING check out his website <http://falkinburgdecoys.weebly.com>)



Ray Muniak Natural Art Pins including Butterfly Pin 'Owen's Choice' (sold at the event \$15 each website <http://muniart.org>)

John Owen Dumm's Original Art Piece, "Toad" (Silent Auction, bid already at \$250)

**Handcrafted Garden Bench** by Phoenix Metal Sales & Fabrication, LLC (website <http://www.guyswithtools.com>)

**JOA Quilt Dresden Plate large rack quilt** by Micki Gura,  
Other great raffle items include: **Kindle Touch**, **Mercedes Benz** yours for the weekend, **4 Disney 1 Day Park Hopper Passes**, **Cedar Point** tickets, **Kings Island** Tickets & an Emerson **32 " HDTV Flat screen** from the Ventura Family



As always, Famous Dave's will kick it up with Ribs on Friday & Family Friendly food Saturday! **Dairy Queen is back with generously giving 100% of sales back to JOA** (Fifth year in a ROW!! Go get some ice cream tonight at the **Sprague Road DQ** will you please!!!) & Antonio's Pizza will keep us full! Oh, and who can forget our awesome desert & beverage shack (thanks Mary Ellen and all of my sister's amazing friends that encourage donations! ☺ )

### **Jett Ride – 7.21.12**

And if we are not blessed enough! A group of 11 teens have been riding their



bikes across our great country to spread awareness about Duchenne called ['The Jett Riders'](#) (click it!) Many are siblings of duchenne and ride for their brother. On 7.20 they will ride to our house and spend the night.... **Where you come in is SATURDAY MORNING 7.21.12..... at 8:30 am we will send this awesome group off to the Jersey Shore from our North Royalton Drug Mart (corner of State and Wallings) – we need to**

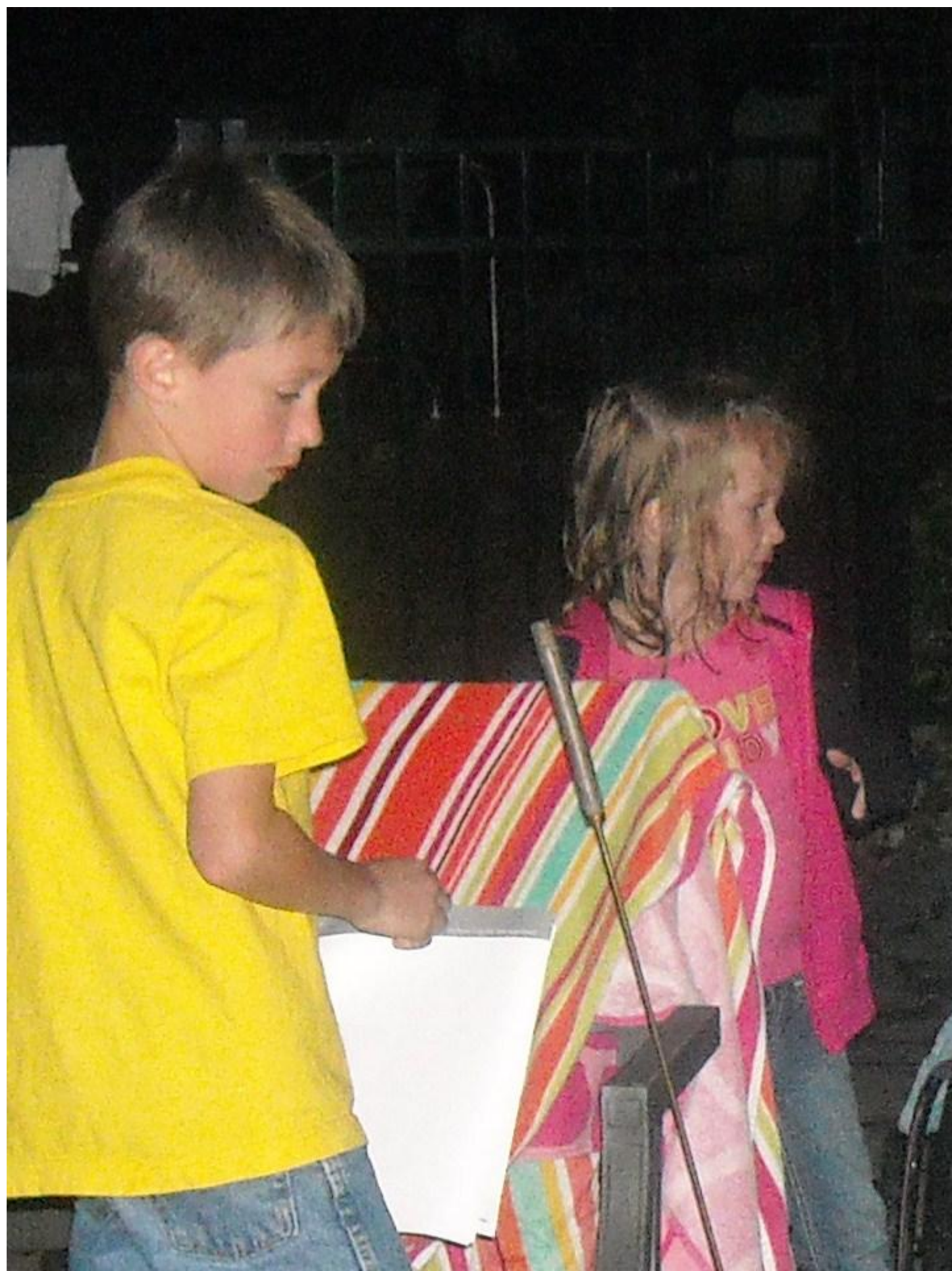
show these kids that JOA is behind their 1,500 mile trek cross country and that we appreciate these young Heroes. Special thanks to Mayor Stefanik that has worked hard to rally our great city! Thank you again for reading our update and we look forward to your generous support in these weeks. This looks to be the last 2012 event we will host – so please make it one that our Duchenne boys will be able to look back on and smile..... heck ... how about let them WALK AGAIN????????

See you soon.... your ever loving JOA Dumm family...ever loving!

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**Summer 2012....Bring it on!** 6.14.12

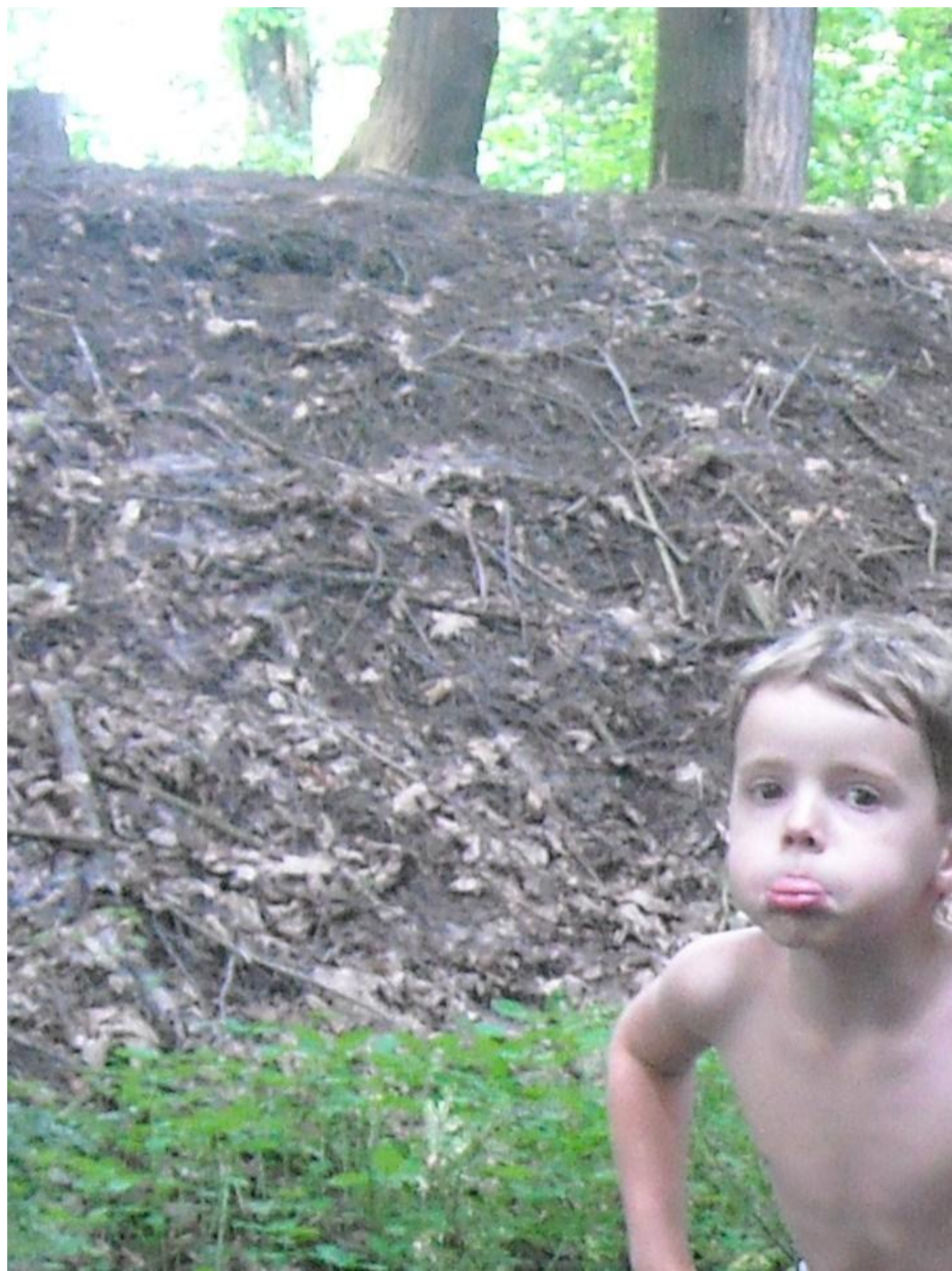
Just wrapped up an action packed summer kick off weekend including burning homework,



Weston's Graduation from College and our annual food fight. The first *Swim Tuesdays* was great fun and an awesome reminder of how blessed we are with the fellowship of our friends....yep it is officially summer at the Dumm's and our arms are open in full embrace to it. My sister jokingly said she was going to keep track of the parties we have this summer, I laughed and said 'well just count every weekend.' Ya know what a true blessing that we are able to bring such heartfelt memories for our boys each summer! So – if ya wanna come on over – Please just show up – that is what it is all about:

**building memories!**

A recent posting on Facebook from a grieving Duchenne mom brought it all home for me recently. It helped me to remember that none of us is any different. We can each find ourselves helplessly surrounded by tragedy at any hour. We started JOA back in 2008 not for research dollars or for the amazing daily support we feel from each of you or to relish in the hope of a cure. Simply, we started JOA to **celebrate**. Our goal at the first Picnic in th



e Park was to **Celebrate Today** and since then boy have we done that every single God given day!!! If nothing else you get from this update, please, please, please take 5 minutes and go get loving on the people that mean the most to you. Celebrate their life and darn it, celebrate yours!!! None of us know what tomorrow brings and being grateful for each second is what we are all about in our non profit journey, our friends, our family and our lives!! (getting gushy on ya...)

Our Picnic in the Park is in full swing – if you have no

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Annual Weekend of Games, Live Bands, Raffles,  
Texas Hold'em Tournament

**German Central Park, 7863 York Road, Parma, OH 44130 440.230.1555**

\*\*\*\*\*joainc.org\*\*\*\*\*

## Party in the Park

5:00pm—11:00pm



TEXAS  
HOLD 'EM  
NO-LIMIT

**\$75 to Enter \$25 add on & Re-buy in First Hour \$5,000\* in prize money *Must be 21 or older* Registration starts at 6 Cards deal at 7 Register & pay by July 25 for extra \$250 in chips**

Register online: [www.joainc.org](http://www.joainc.org) or pay by check, by July 25 for extra \$250 in chips

## Picnic in the Park

Games, Music, Raffles  
5:00pm—10:00pm

Bring your family and friends and join us for another fun-filled evening to raise money & awareness to fight Duchenne Muscular Dystrophy! *Great food, Raffle Baskets worth over \$30K in products, Music:*

*Burning River Ramblers,*  
*Jabez*  
*The Polka Pirates*

**GAMES, GAMES & MORE GAMES**  
Games for adults and kids,  
Hole in one  
contest , plenty of kids game  
and prizes.

t heard it is **two days this year**- Friday night 7.27.12 is the Party in the Park – 21+ Beer, Bands, Poker and Saturday 7.28.12 is our traditional Picnic in the Park. We so hope you can come out and support one night with JOA! [Click here for the Poster](#) – we would be honored if you would share this with your workplace, friends and family! Famous Dave's, Dq Polka Pirates, Jabez Burning River Ramblers, Liverpool Lads, Masters of Disaster and Squish the Band will keep you full and rocking both nights!

Texas Hold em - [Sign up here](#)! Share this link, will ya?

**We so need your generous help again this summer** – please sign up [here to volunteer](#) for either night. As well are also looking for more high-end donations... concert tickets and what not – anything at all actually would be a huge help! Send me an email at [jen@joainc.org](mailto:jen@joainc.org) if you can help.

Please don't forget to support our awesome [JOA Picnic in the Park Sponsors](#)!!

Our Moving Spirit Team did an amazing job at the Cleveland Rite Aid Marathon. We raised over \$16,000 and had t



he support of 65 runners! It was a blast! Saturday, 6.16 we meet again and this time at the Rotary Club of [Strongsville Run4Fun](#). Please consider joining us Saturday morning! Our dear friend Ruth Crane has set her sights on the Akron Marathon in September to raise funds and awareness for her wonderful non-profit, [Ears to You](#) – let me know if you are interested and I can hook you up!

The boys closed out the school year with a bang.



Owen's First Communion was beautiful, it really brought tears to our family and friends when we rolled down the aisle! (pictured with his Godmother, Aunt Monica) Under the steady and loving hand of Mrs. Tyler, Owen will head into third grade and Rutger easily into fifth grade. Wade will be off to full day Kindergarten with our beloved Ms. Lucarelli in the fall. It is so hard to let them grow up .....so we are soaking up the sun and so thrilled that summer is here. We plan to do lots of hanging out so please stop on over any time!



Don't forget to register for the so fun Scavenger Hunt in Put-n-Bay 8.11.12 hosted by our Sister and Brother in law. What a blast this is and it raises \$

and awareness for Juvenile Diabetes! Call Dee at 440.871.6432 to reserve your spot – we will be there so should you!

Hope you don't mind, but we will hit ya with another update early July with the Raffle List for our Picnic weekend! To date we are over \$20,000 in prizes. I keep saying to all – it is not about the \$ we raise it is all about the feeling of celebrating Life! **Help us keep that alive by joining us on 7.27 or 7.28 or heck – Why not both?**

Don't forget - our Jett Riders will be at our house 7.20.12 - plan on coming for a great BBQ and celebrating these teens that are biking 1,500 miles to derail Duchenne.

Thanks for all the love and prayers believe me – we feel them all! For those that do not know, a generous outpouring of love and spirit has culminated at the Dumm Household since Christmas. Through the generosity of a St. Albert Group called Lift Them Up, we are able to start our



elevator project. This shovel ready project will kick in within 2 weeks and before you know it – Owen will have independence and a great new room on the second floor. If that is not celebrating life, I really do not know what is.

God bless you and mostly THANK YOU!!! Now go get loving .....  
The Dumms

~~~~~

~Joy~ 4.15.12

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For the past 3+ months, we have been struggling with the muscles in Owen's legs that decided to take a permanent rest. He did not go from slow to slower – he went from slow to stop in a matter of 2 weeks. There are no



answers, and yes, an answer would be nice, it will not change the decisions his muscles made (without asking any of us, even Owen, those greedy buggers!). So you would think that we are faced with a whole new set of sadness to embrace as we figure

out how to keep him moving, upright, walking and not allow him to be completely wheelchair bound (yet, though we know it is on the way).

Actually, we did good. We had this thing in our hearts – we have actually had in there for a very long time – I think even before kids – and it took me sitting through a meeting recently at St. Albert the Great to realize what that constant thing I have been so fortunate to have all of my life – Mrs. Seislove started the meeting with an awesome reflection taken from the theme of the seven most successful habits – but this was for us Catholics. One of the seven habits str



uck my core and gave me a confirming pause... ahhh ... a name ... I can't quote her exactly but I hear her often stating ... "In whatever you do have JOY in it, untamed, uncontrollable

JOY, find Joy in everything you do...." She said it much more eloquently but the message stuck.

We might not have muscles – but we have Joy darn it! And we do the absolute best in cultivating it in every precious life second we get. To the point that some times I really feel sorry for those that can't experience the Joy that God gives each of us – letting doubt, worry, sadness overshadow. Well that I think is for another story.....

### **Thank you**

I know for certain that you sustain our Joy through all the never ending support & the generous ways you contribute to JOA (birthday gift donations, selfless giving of time and talent, the list goes on). We continue to be in awe with the overwhelming support from my family, our friends, parish and community, not only in every JOA event but the recent efforts to support our personal needs. This brings so much **Joy** ~ it is unbelievable!! Thank you is not enough!

### **JOA 2012 EVENTS**

We have so much going on with JOA that I can barely wrap my mind around it. The involvement of our community is AWESOME! So much that I think if you are not on board, you are going to regret it!

#### **4.26.12**

Join us for a Duchenne Parent Education Outreach meeting near Toledo. Our good friends, The Henegar's are hosting a Cure Duchenne educational meeting with speaker Dr. Michael Kelly, CureDuchenne Chief Scientific Officer. Email Tammy Henegar at [thenegar2000@hotmail.com](mailto:thenegar2000@hotmail.com) with questions or to rsvp - Click [here for more](#) info 6:30 p.m. – 8:00 p.m. at The Hilton Garden Hotel

*6165 Levis Commons Blvd Perrysburg, OH 43551*



#### **5.20.12**

Moving Spirit has kicked it into gear with 55 Spirit Runners for the Rite Aid Cleveland Marathon. We run together weekly and have forged so many new friendships. Casual runner, committed runner or just curious... join us anytime - email me and I will set you

up ~ [jen@joainc.org](mailto:jen@joainc.org).



**6.16.12**

The Strongsville Rotary Fun Run will honor JOA as their charity of choice! We are so blessed to have the support of the Strongsville Rotary – I am sure you will see a ton of our Spirit Runners there so plan on joining us for a quick 5 k. Sign up [here](#)

**7.20.12 and 7.21.12** We welcome the [Jett Riders](#) to our home. This is a group of teens and chaperones that ride their bicycles from Minneapolis,



MN to Point Pleasant, NJ starting July 1 to August 3 to raise awareness for Duchenne. Many of these kids have brothers with Duchenne. They decided to settle in on North Royalton for one stop on their 1,500 mile route. We will host a huge JOA BBQ at our house – so consider this your invitation to join us to celebrate these amazing kids. The city of North Royalton will send them off Saturday morning at 9 am complete with a Police Escort out of the city! Any cyclist out there that wants to do a day ride with them [click here](#) – they are off to Mansfield from North Royalton! What a blessing! If you would like to support Team JOA [click here](#).



**The Summer Event**  
**Yep we are on for two nights baby! Get it on your calendar already before you plan your vacation and miss it!**

**7.27.12** Friday Night plan a date night with you special someone for the **Party in the Park**: Bands, Beer and Poker – you will love it

**7.28.12** Saturday Night – **Picnic in the Park** - our traditional family oriented night will kick off its fifth year. We are so sad that Lawless has retired they will be missed. As always we are so excited about this event that draws 2,000 of our friends and family. Micki Gura is at her best raising donations, so if she calls on you open your heart to her as you always do!

**9.??.12**

We are considering a **Cycle in September** – not sure of details but if anyone out there feels moved to plan it – we are all peddles on that one baby!!!!

**The boys....**

We had a fantastic Easter break with lots of family time. Owen will make his First Communion in May and continues to do very well at St. Albert the Great – great grades, great friends, great teachers – Great Owen!



I do have to share that he has these new full leg casts he is breaking in. They help him to stand upright on his own (which he cannot do) So we have been breaking them in – so much so that he took my breath away the other day – I strapped him in, pulled him up from the floor and had my arms and hands ready to support him as we moved together to the table to stand..... he gently pushed my hands away and took 4 steps on his own. He has not done that since Christmas..... then when Tony got home he took 8 more .... To see your child walk on his own after 3 months of not walking is one of those **Joys** that I get to keep with me always.

Rutger will be sporting braces very soon and is glad that summer is on the way. He did a ton of



hunting this winter with Tony - he shot his first button buck this season. He is a tremendous big brother, friend and son. He is officially in charge of the game in our house – you may think board game... ah no... 'game' we have five new chicks staying warm in our living room until they are old enough for the coop. He is a very compassionate caregiver to these younglings – our poor dogs are going to have a nervous breakdown staring at these succulent chicks!!! But Rutger does a great job in keeping them at bay!

Wade is itching like mad to be in K, hopefully his best friend Joseph will be in the same class. Wade





community and have such genuinely amazing friends! Happy New Year to each of you, we hope it is filled with the tiny miracles each one of us needs!

JOA [Moving Spirit](#) kicks off this month. This is a team of trainers ready to help you walk or run the 5 k, 10 k , ½ or full marathon on **5.20.12** at the Cleveland Rite Aid. What is so great about this group is the fellowship we have already started through encouraging each other to get out there and exercise. New Years is a perfect time to reflect on



your health goals for the coming year, make this the year you change your life and make getting in shape your priority. [Join Moving Spirit today](#). (PS sign up by 1.6 to take advantage of the discount)

We are honored to be the charity recipient to the Strongsville Rotary Club's fourth annual Fun Run; a 5K run and 1K walk on **June 16 at 8 am**. The run is coordinated through Hermes – Cleveland. Please mark your calendars for this great local event.

The New Year means time to turn our efforts to the **Picnic in the Park 7/27 and 7/28!** Two



days this year ~ We are super excited to plan two great nights to bring you. So far the plan is Friday night to be a poker, band and beer kind of night and Saturday will host our fantastic family centered Picnic in the Park. German Central is the place and as always we are looking for as much support as we can muster! **Please mark your calendars**

**Have you noticed the new feel around here yet? We have updated our website, doesn't it look amazing? If you have not browsed through here lately ~ please take some time and look around. A special thanks to Natalie Guzzo, our Marketing Director for all**



her hard work in creating this for us. Hey check out the volunteer tab if you are interested in helping out.

**So what is going on around the Dumm Household?**

**Fourth Grade for Rutger is proving to be rough but he is holding his own. He is doing very well wrestling and I get a kick out of him and Tony watching college wrestling... since we are not sports watchers this is always something cool to watch. I love to see passion at work especially in our kids. He did get his first squirrel a few weeks back with a 410 shotgun. He served it up on Christmas Eve ~ there was just enough to go around and I guess you**



can say yes we do have a bit of hillbilly in us but that is just how we roll..... Wade is bursting out wanting to be so much older than five. It is impossible that he is not a toddler anymore. He literally grew up so fast and is doing well at Royal Redeemer ~ I can't believe we are talking K next year. As long as his best friend Joey can be with him in class, all will be well! And yes, his plan is still to be a great swordsman one day and defend our family against any evil empire!



**And you know~ 2012 would not be the same without a Wade story ~ New Years Eve we had sparkling grape juice in champagne flutes ~ he was so thrilled to have "farkling (sparkling) wine in a fseial (special) glass" that I had to send a picture to Aunt Dee..gosh he cracks us up. John Owen is kickin in the grades at St. Albert in second grade. We continue to be proud of him as he prepares this week for his first reconciliation just prior to his eight birthday. He continues to be blessed with abundant friendships and plenty of new Lego's! His muscles are not cooperating much lately as his weakness is becoming more apparent. It kind of feels like a freight train out of control. He is taking it in stride as**



**Tony and I are on the sidelines just trying to keep up and figure it all out. There are no words that describe how to feel when one day your child could get up from the table, get his breakfast and sit back down and the next day, he can't, he simply just can't.**

**We are so blessed with our strong family and great friends. One of Owen's good friends pretty much summed it up in one of his school assignments... The question was, "How does God help me to use my gifts well?" His answer was, "God gave me Owen to help because he needs a good helper that cares about him." Even though his muscles are failing him, clearly his friends are not. And for that we are all very blessed.**

**Tony and I enjoyed our Christmas immensely ~ we got to spend lots of quality time with each other, the boys and our family.**



**We are looking forward to some good heavy snow so the boys can sled ride and start enjoying winter.**

**We continue to be grateful for your ever-loving support! We humbly ask for your support through 2012. We have our runs planned and our picnic in the park, we know we cannot derail duchenne without you. Please keep the prayers coming especially for Strength and Endurance for John Owen and all our DMD guys.**

**God Bless and Happy New Year ~ now go get loving on those that mean the most to you ~ constantly remember that each day is a gift!**

## **Thanksgivings..... 11/12/11**

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It feels like so long ago since we sent an update your way.... Here we are approaching Thanksgiving and the rush of the Holiday Season.....2011 is just flying by!



We truly had an amazing September 11 – what a fantastic way to commemorate our heroes of 9-11 by creating more heroes! We hosted our first run and with 98 participants and \$4,000+ raised, I would say it was a great success. This progressive marathon supported and honored our Mo Joe Marathon Dad, Joe Vasil. The day had every element of weather – rain, hail and sun just as our race began. As my



sister put it plainly –"God does not rain on John Owen!" We continue to be humbled by the outpouring from our St. Albert the Great family as you see in this picture, they were aptly represented! Thank you to every one that got your mo joe on at our first marathon!

And of course, we have to discuss the Big 2011 Event ~ as Joe Vasil really put that Mo Joe in motion on 10/1 and 10/2 running back to back marathons for John Owen. He certainly derailed duchenne with raising \$14,568 for PPMD! Please read his [race report](#)



– Joe, Jeannine and Kyle are a permanent part of our JOA family and we are eternally grateful!

So you would think that running 52.4 miles in less than 48 hours and raising close to 15 G's would be enough for our Mo Joe? Nope... think again. He has championed the [*Moving Spirit*](#), which is a group of running coaches training any JOA fan (yes that means you!) out there for the Rite Aid Cleveland Race: 5k, 10k, half marathon or full. What



an amazing gift Joe continues to give JOA blessing us with his talents and inspiring others to get on board to derail duchenne. Please check this [link](#) out and share with all of your friends... you never know who has that running bug.

The boys are doing well. We had a bang up time on Halloween at Aunt Dee & Uncle Greg's – hordes of candy and great time!



Wade of course continues to do what the youngest in most families do, keep us laughing with his antics as he vies for attention😊. He continues to crack us up like with his latest Wade'ism' - the other day Rutger was having trouble with the computer and I told him to close the windows. I must have had a worrisome tone for Wade spouted out "Don't worry, if you close a window you can always open the door!" He is doing very well at Royal Redeemer Pre-School and of course is having a blast with his best bud Joseph – they hit Lego Fest together this month and none of us will ever look at Lego's the same!

Rutger has started wrestling again with the City of North Royalton. He is doing great in the forth grade, though it is much more challenging than any

of us anticipated, but he is doing well! He scored a special trip with Tony in the UP of Michigan this fall, salmon fis



hing... by the
second day he was tying flies, casting and reeling in the big ones on his own! He had a blast as did Tony teaching and watching... thanks Uncle Bob!! As far as Owen; we have some big news... he got out of the car by himself today! You might not think that is newsworthy... I mean kids get in and out of cars flawlessly everyday. I actually thought it was impossible for John Owen. Ya see, we have *always* gotten him in and out of the car.. we have a crazy, huge SUV... so never would I imagine not helping him. Well in between errands, we stopped at the house and he wanted to wait in the car. Next thing I knew, the door opened and there was



Owen walking in the house.... Shocked I asked how he got here, with a simple reply he said "I wanted to come in, so I got out of the car and came in." Lesson learned for me...though his muscles are weak, his determination is so strong and we need to keep reminding ourselves of what he CAN DO not what he cannot. He has a huge year with First Communion in May. He is excited about this sacrament, reconciliation in January and has been diligent in preparing for both! School is awesome – grades are very good which is a huge blessing for us. We so love Mrs. Tyler and all our second grade teachers (and students) that take such good, loving care of him.

On the health news....He is getting fancy new leg braces, they are made from carbon fiber and look pretty cool, like two prongs of steel holding him up. He

is holding his own, though visibly weaker as he asks for help walking pretty much daily now. Exon skipping is still going on only two hours south of us in Columbus, OH. Here is an excellent [article about exon skipping](#) and how (if proven safe) can help Owen and other DMD guys .

We were blessed with two surprise events this past month: Ray & Barb M



uniak (Grandma and Grandpa) hosted a Polish Night at their community center in honor of JOA! Clipped Wings United Airlines has also taken JOA under its 'wing'... both resulting in generous donations and giving JOA an opportunity for new fans! Thank you both!

We are gearing up for turkey, mashed potatoes and fantastic family memories in the next few weeks. As we gather around the table on

Thanksgiving we will keep you in our thoughts, for your support continues to lift our spirits as we face this daily journey with Duchenne.

Christmas cheer will soon follow and we so hope that the last weeks of 2011 are blessed and filled with Joy! Go on and get loving on those you hold dear and always thank God for all you Can Do!!

Until 2012, God bless you,

Tony, Jen, Rutger, John Owen & Wade

Btw...Rumor has it I am training for the Cleveland Marathon..... well not quite marathon material yet, but I do hope to complete the 10k through [Moving Spirit](#). Please consider joining me as I train to derail duchenne one-step at a time! Believe me, if I can do it, so can you!

Derailing Duchenne.... one summer at a time August 29, 2011

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Well here we are with Labor Day fast approaching. You know what that means to the MDA don't ya? Yep Telethon and Fill the Boot Weekend! Gotta love our Northeast Ohio Firemen they really do work hard for all of us! If you are out and about give that boot a fill for JO will ya? We had a fabulous summer! The Picnic in the Park was the showstopper for all of us – record crowds an



**d over \$30,000 will be sent to JDRF, MDA and Parent Project Muscular Dystrophy all to help cure our kiddos. Thank you for your undying support! We had so much fun that we have decided to make this a weekend event next year ~ so get up now ~ go to your 2012 calendar and reserve 7/27 and 7/28 for JOA baby!**

**Thank you is not enough to all our family, friends, volunteers and sponsors. Please visit our sponsor page, shop them, and thank them!**

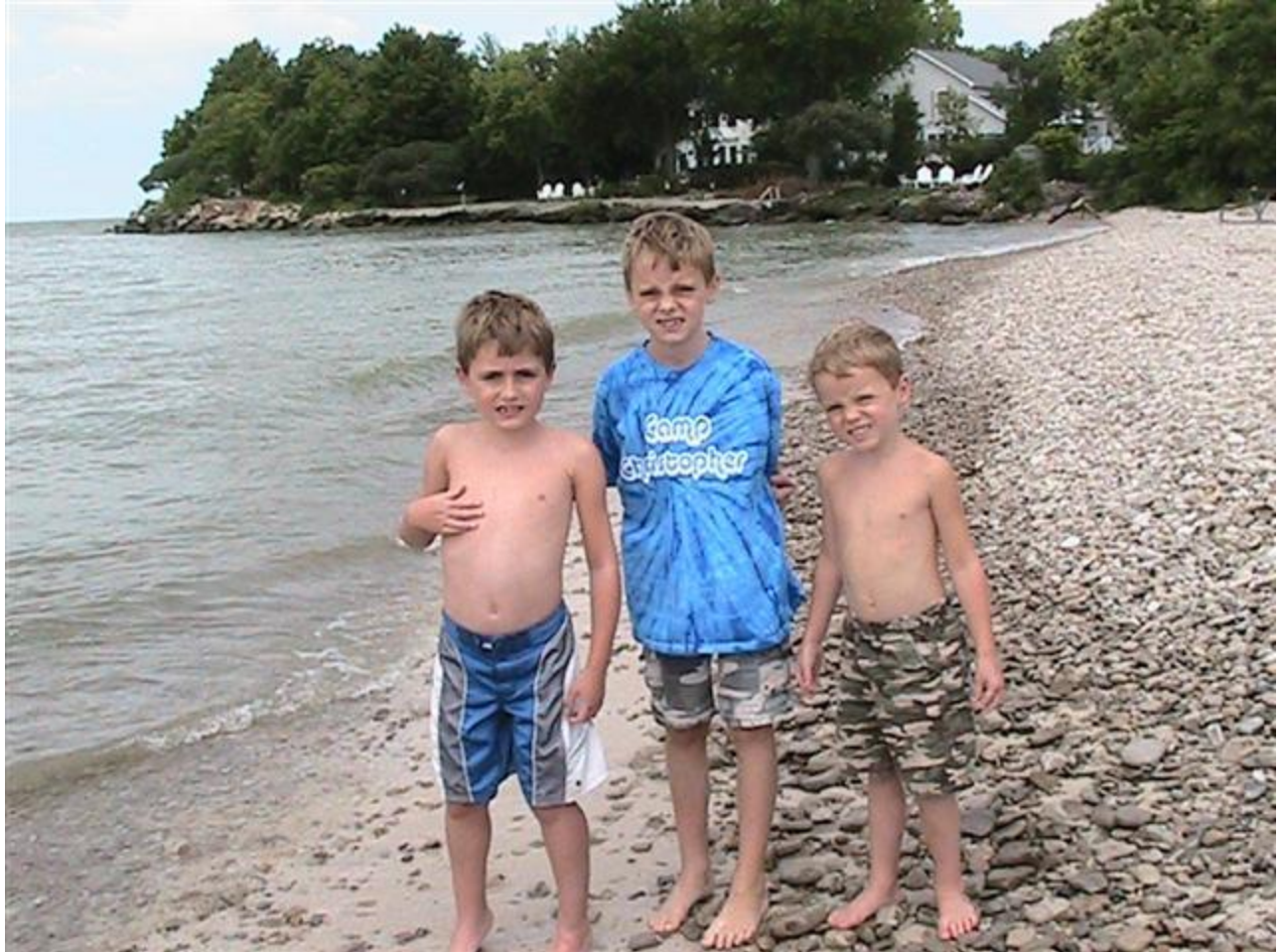
**We had a whopper of a thank you party for our volunteers this past Saturday. The yard, pool,**



**house and hot tub were filled to the brim with our amazing volunteers!**

**Thank you guys so much!**

**School has started ~ so sad that summer is over. We were able to get away for a family weekend at Catawba and Put in Bay, it was just perfect! We then went to PA for our shooting week with our friends and again, Bryan Cooke was the long-range 600-yard competition winner**



using a Remington 40xb with a spring field armory scope. Needless to say, since this is his second year winning, Tony, Opa, Bob, Bruce and Larry might not ask him back.... just kidding Bryan.. but next year Bryan you have to use your own gun! :)

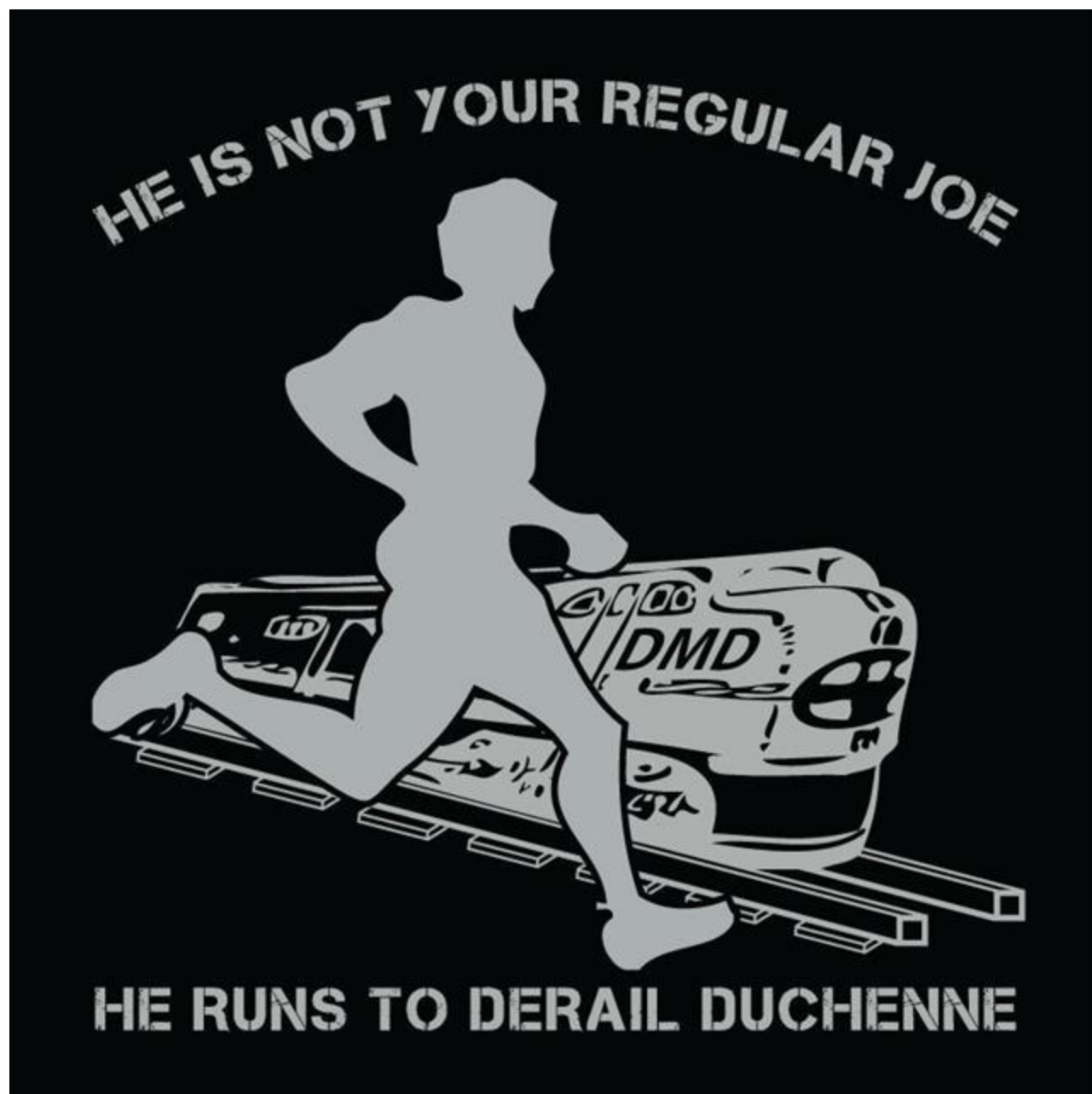
What a blessing our life continues to be. This fantastic memory filled summer, our dedicated and amazing family and constant friends. I am certain that this adventure will continue to keep our hearts light and spirits high!

**Rutger is looking forward to his special fishing trip with**



**Tony in September. John Owen loves that he gets to use his scooter in between classes at school ... and then there is Wade~He starts 4 yr old preschool on 9/12 with his best friend Joseph and already he has educated us about many things ~ like the other day two of the small toads that Rutger caught were sitting on top of each other. He called me over and said "Mom, those toads are a girl and a boy and you know how I know that ?" I said, "No" he said "Because they are meeting" (he meant *mating*.... Too funny). Gotta love um.**

**We h**



ave two more events yet this year – 9/7 [Mo Joe Happy Hour](#) at BW3 in Str



Strongsville, consider coming please - \$15 to support an amazing runner. Then our first marathon, the Mo Joe Marathon on 9/11 also in Strongsville and also to support our Mo Joe, Joe Vasil who will be running back to back marathons for JO on 10/1 and 10/2 [click here to learn about his run.](#) Keep those prayers coming for him and for all our DMD guys. Exon skipping has started in Columbus – just 2 hours away from us - the scientists are working hard to derail the course of this dreadful disease. Here is the most recent link on it – [check it out](#) and pray that these boys show excellent progress and health! Go Bucks and go get loving on the ones you love.... Soak it in baby ....life is good

God bless you!

Tony, Jen, Rutger, John Owen and Wade

Oh yeah, don't forget Coach to Cure 9/25/11 ~ Football across the U.S. will promote Coach to Cure MD ~ AWESOME

**Picnic in the Park ~ What a Blast**



Thank you for the awesome time at German Central on Friday on 7/29/11! Lawless, Northeast Ohio's Premiere Country Band, The Polka Pirates, Jabez, Famous Dave's, DQ, Augies & awesome sponsors and amazing auction items certainly derailed Duchenne \$30,000 to send to research! Thanks much - save the date for 2010 7-27 12! More to come soon.... 8-7-11

**PLEASE CLICK ON PAST UPDATES FOR MORE!**