



Where should we begin! It has been almost a year now since our last benefit shoot. Let us start by telling you our journey. We are the Harvey's, Kevin, Chantel, Kobe, and our six year old son Devin. For those of you that don't know Devin, he was a young boy, full of life and so outgoing. Devin was diagnosed with Adrenoleukodystrophy (ALD) in May of 2013. ALD is a rare genetic disorder that causes damage to the myelin sheath, an insulating membrane that surrounds nerve cells in the brain. The childhood cerebral form is the most severe, with onset between 4-10 years old. The most common symptoms are usually behavioral changes such as abnormal withdrawal or aggression or poor school performance. Other symptoms include vision loss, learning disabilities, seizures, deafness, and fatigue. There is no cure for this disease. Prognosis is generally poor due to progressive neurological deterioration unless a bone marrow transplant can be performed in the early stages. Devin's prognosis was estimated to be 18-24 months.

Our hope a year ago was that an experimental Mesenchymal Stem Cell transplant was going to stop the progression of his disease. Devin underwent a transplant in July 2013. In September, after several MRI's, we found out the disease was still progressing. The Doctors in Minnesota then wanted to try a drug called Tysabri which is used for Multiple Sclerosis. Devin was on the drug for four months, with one infusion every four weeks. During the Tysabri treatments we flew to Muscat, Oman for another experimental stem cell treatment. As time passed Devin was beginning to regress more and more. Devin had completely lost his vision and his hearing was getting worse by the day. As parents we were devastated knowing where he was headed. After putting Devin to sleep at night we would stay up praying, studying the disease, and hoping to find our next step if all this had not worked. The next MRI came in November and again the disease was still progressing. This news only made us angrier knowing this disease was taking over our son's body and there was nothing we could do. We weren't stopping. We found another clinic in Cancun where they specialize in using autologous stem cells with growth factors. This procedure was performed in late November. By January his ability to walk was also taken away and his speech was very slurred from the progression of this disease. In February his speech and his ability to swallow was taken, so we decided to have a feeding tube placed at Children's Hospital. Devin was on multiple medications four times a day. He was having tremendous amounts of pain from the muscle spasms. A feeding tube was our only option to get his medication down and keep him comfortable. While in Cancun, we had found another clinic that specialized in gene therapy. Gene therapy is the use of DNA as a drug to treat a disease by delivering therapeutic DNA into a patients cells. A treatment that could perhaps put the gene Devin was lacking, which is the ABCD1 gene, back into his body via lumbar puncture and stop the disease for good. This doctor was contacted while in Cancun and he said he would accept Devin's case. The Gene Therapy would take up to 8 weeks to grow. Devin had this procedure at the end of February in Bogota, Columbia. This treatment could take up to six months to work. Devin had an 8 week post therapy MRI done and it still showed progression. We have not given up hope and are praying hard that this therapy just needs more time to fully do its job. While this gene therapy is doing what it is designed to do, we are still researching for that next step. The next step would be remyelination of the brain but unfortunately this is not being researched for ALD. Seems like the stopping point but we can't stop now. We will pursue every option we can for our loving son Devin.

Thanks for all the generosity and support everyone has given in this difficult time in our lives. We appreciate everything everyone has done and is doing for our family.

Sincerely The Harvey's – Kevin, Chantel, Kobe, and of course Devin



August 16, 2014
TRI-PARISH SPORTING CLAYS, HOUMA, LA
TAX ID#: 46-2830211

REGISTRATION FORM

Sponsor Name:
Address:
City/State/Zip:
Email:
Telephone Number:

Preferred Main Event Shooting Time: (Circle One) **8:00 a.m.** **11:00 a.m.** **2:00 p.m.**



Team Captain	T-Shirt M/L/XL/2XL/3XL	Address	City/State/Zip	Phone/Email
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Team Member #2	T-Shirt M/L/XL/2XL/3XL	Address	City/State/Zip	Phone/Email
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Team Member #3	T-Shirt M/L/XL/2XL/3XL	Address	City/State/Zip	Phone/Email
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Team Member #4	T-Shirt M/L/XL/2XL/3XL	Address	City/State/Zip	Phone/Email
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Team Member #5	T-Shirt M/L/XL/2XL/3XL	Address	City/State/Zip	Phone/Email
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**A.L.D Sporting Clay Invitational
TEAM PACKAGES**

Tournament Sponsor Team Pkg. - Two (2) Five Man Team Pkg Includes: Main Event (100 Shots ea.Team Member), 5-Stand (25 shots ea.Team Member) Long Bird (5 Tickets 5 clays (10 Shots ea.) 1 per Team Member), 2 Man Frenzy (3 Score Cards per 5 man Team), and per flight on course poker run. LOGO on Tournament Banner, Name on T-Shirt

Package Total: **\$2,000.00** **Qty:** _____

Five Man Team Pkg. Includes: Main Event (100 Shots ea. Team Member), 5-Stand (25 Shots ea. Team Member) Long Bird (5 Tickets 10 Shots ea. Team Member), 2 Man Frenzy (3 Score Cards per 5 man Team), and per flight on course Team Poker Run.

Package Total: **\$700.00** **Qty:** _____

Five Man Team Includes: Main Event (100 Shots ea.Team Member) and per flight on course Team Poker Run.

Package Total: **\$500.00** **Qty:** _____

Additional events may be purchased as follows:

Two-Man Frenzy (25 Clays)	\$25.00 each	_____
Long Bird (5 Clays 2 Shot Single Gun)	\$10.00 each	_____

- * 5 Stand will open on Friday 8/15/2014 at 4pm and until Dark**
- * 5-Stand will be scheduled for teams.**
- * Event will occur rain or shine. All Participants are responsible for providing their own shell and ear protection for the event.**
- * All teams will be flighted per the times requested on a first come, first paid basis.**

***In the event this tournament needs to be spread across two days, the tournament will start on Friday August 15, 2014. Friday's Flight time would start at 2pm please indicate if you are able to shoot on Friday's flight when registering.**

Able to Shoot on Fri. _____

A.L.D Sporting Clay Invitational SPONSORSHIP OPPORTUNITIES

Tournament Sponsor (Listed under Team Packages)

Station Sponsors *(Sold on first come, first paid basis)*

Main Event Stations 1 thru 11 Qty: _____ \$100.00 _____

Logo on sign at station

Additional Stations *(Sold on first come, first paid basis)*

5 Stand Logo on banner at 5- Stand \$500.00 _____

Two-Man Frenzy Logo on sign at Two Man Frenzy \$200.00 _____

Long Bird Logo on sign at Long Bird \$200.00 _____

T-Shirt Sponsors *(Sold on first come, first paid basis)*

Sleeve 1 & 2 Logo on Sleeve \$200.00 _____

Back of Shirt Company Name on back of shirt \$100.00 _____

Gun Sponsors

Bronze Sponsor Qty: _____ \$250.00 _____

Silver Sponsor Qty: _____ \$500.00 _____

Gold Sponsor Qty: _____ \$1,000.00 _____

Total Amount Due: \$ _____

All checks should be made payable to Devin Harvey Benefit

Payments by credit card will be charged a 6% fee.

Credit Card # _____ Ex. _____/_____

Visa M/C AMEXP Security # _____

Name on Card: _____

Address on Card: _____

City/State/Zip: _____

Credit Card Signature: _____

Mail this form along with your payment to:

Devin Harvey Shooting for a Cure ALD 2013 Sporting Clay Invitational

c/o Devin Harvey Benefit

P.O. Box 5033

Houma, La. 70363

For questions or additional information contact:

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