

Shirley has become a man of many hats — and teams.



By Scott Shirley

Stronger Every Day

As Uplifting Athletes' influence spreads to other schools, the organization's founder and executive director offers first-person insight into the hurdles that had to be cleared before the growth could begin

It's not often that I take the time — or make the time — to do so, but every now and then, something happens that encourages me to look back and say “wow.” Feb. 28 was one of those days. I was at Third Base Restaurant in Austin, watching Texas football players compete against one another in EA Sports NCAA Football '10 as part of Global Rare Disease Day.

After Longhorns defensive back Clark Ford claimed the campus championship belt in Austin, he was matched up against West Virginia linebacker J.T. Thomas, who was wearing his title belt in Morgantown. The players, fans and media had a blast watching these two college football stars going head-to-head (with 1,400 miles between them) via Xbox LIVE. What made it even more entertaining was the interaction between everyone at the two sites. A Skype video feed on one TV allowed the players and fans to see each other while communicating (trash talking)

The dire prognosis for Don Shirley moved his son to action.



Submitted by Scott Shirley

Jones, Shirley and Costlow
in the early days.



Submitted by Scott Shirley

via Twitter on another screen. For better or worse, Texas and Penn State both got knocked out of the tournament that day before crossing paths. However, it would have really come full circle for me if the teams went head-to-head and the Skype video allowed me to be a part of the event in State College that afternoon, which is where all of this started a few years ago.

The 2010 Uplifting Athletes Video Game Challenge featured 48 college football players from Penn State, Ohio State, Texas, Georgia, Virginia and West Virginia. It required the assistance of about 20 volunteers and coordination between all of the football programs, restaurants and local GameStop stores.

The purpose of the event was no different than any other Uplifting Athletes event — to use college football as a platform to connect fans to the rare disease cause. Our efforts generated buzz locally and nationally. And it was only one of the events we had planned that weekend. Others included an advocacy day in Washington, D.C., a team marathon in Tampa, a Rare Disease Night during winter sports contests (including a blood drive), and the crowning of the Rare Disease Champion, which is awarded annually to a leader in sports who realizes the position they are in to make a positive and lasting impact on the rare disease community. More than 20,000 votes were cast on our Web site, with Dickenson quarterback Ian Mitchell winning for his efforts to raise \$95,000 in memory of a childhood friend who lost his life to a rare disease.

We would not have dreamed in 2003, the year Uplifting Athletes was established, that any of this was possible. To be honest, we might have even laughed nervously at all of these ideas a year ago. But it was possible, and the potential is endless.

A Simple Plan

Uplifting Athletes started with an innocent conversation between two college football players. The story has been well documented, but I never mind sharing the details. In the fall of

2002, I was a receiver with the Penn State football team. I was on my way home from practice one day when my cell phone rang. When I saw my mom's name on the screen, my heart dropped to my stomach. It was one of those calls that I knew was going to bring bad news. Sure enough, I answered the phone and she was so choked up that she couldn't even talk. I pulled into the parking lot in front of the Nittany Lion Inn while she composed herself enough to tell me that my father had been diagnosed with renal cell carcinoma (commonly known as kidney cancer). They were told that he'd be lucky to see me graduate six months later.

Thanks to Coach Joe Paterno's teachings (you're never as good as you think you are when you win, and you're never as bad as you think you are when you lose), I had developed a pretty level head. You hear about people beating cancer all the time, right? My dad had lived a healthy lifestyle — he didn't drink or smoke and remained active as a high school baseball coach for 30-plus years. He was a fighter. He was going to be a survivor. Everything was going to be OK.

That fall, I went with my parents to the best medical centers in the mid-Atlantic region. Everywhere we went, though, we were told that nothing could be done. In my mind, that meant we just hadn't found the right doctor yet. We finally got a referral to Johns Hopkins, which in my mind was like going to see the Wizard of Oz. As excited as I was to go, I was equally heartbroken when we left. The doctor didn't even stay in the room long enough to close the door. All he said was that there was nothing they could do.

On the way back to State College, it hit me that there had to be more to this story. So I called the American Cancer Society and was told that kidney cancer does not typically respond to standard first-line treatments such as chemotherapy or radiation and is not one of the organization's priorities. They were sorry, and I was now more desperate. My next call was to the Kidney Cancer Association.

That is when I learned why nothing could be done: Kidney cancer affected fewer than 200,000 Americans and was classified as a “rare disease,” meaning there was little financial incentive to make and market new treatments.

The rest of the trip home left me plenty of time to think. I had always assumed that cancer was cancer. I never considered different cancers to be different diseases. But they are. Different molecular pathologies. Different treatment protocols.

So now what? By the time I walked into my apartment, I was pretty aggravated. My roommate and teammate, Damone Jones, was sitting on the couch watching TV and greeted me as usual. Except this time, when he asked how my day was, I expressed my frustration with the situation that my family was facing. It wasn't that “nothing could be done.” It was that it wasn't important enough to do anything. Without hesitation, Damone shrugged his shoulders and suggested that we do something. “We're Penn State players,” he said. “If we do something stupid, it's on the front page of the papers. Let's take advantage of the position that we're in and use that spotlight to make a difference.”

Success With Honor

Damone and I started brainstorming in the locker room, and the team rallied around the idea of taking our summer lifting competition, opening it up to the public and using it as an opportunity to raise some money and tell our story about kidney cancer as a rare disease. So we talked with the coaches and approached administrators. They encouraged us to run with it.

At the same time, my family had been referred by the Kidney Cancer Association to a specialist at UPMC. The doctor suggested surgery, and we did not hesitate. It was a complicated procedure, as the tumor touched five vital organs and was starting to encroach on his vena cava. Surgeons had to remove two ribs and go through the diaphragm just to access it. A second procedure removed half of his left lung because the cancer had metastasized before it was found.

My family spent Easter together in the hospital. While I was there, teammate Dave Costlow called to see how things were going. He had heard about what Damone and I were trying to organize and offered to help. Dave saw it not only as an opportunity to leverage our position as college football players but also as an opportunity to get some real-world management experience, since our year-round commitment to football made it difficult to participate in off-

campus internship opportunities. So Damone, Dave and I approached Deloris Brobeck, football's academic services assistant, because we knew we were going to need some help. She knew we were up to something when we walked into her office with smiles from ear to ear. Seven years later, Lift For Life is still her baby!

We quickly realized that the benefits far exceeded our expectations. Teammates were lining up to help. Our organizing committee would meet at night in the Lasch Building, sitting around a table trying to figure out how to do what we wanted to do. It really was like running a small business. We were responsible for the promotions, operations, finance, etc. If there was something that we didn't know how to do, we asked a teammate who was in that major. If he didn't know how to do it, he asked one of his professors. They



Star players like Michael Robinson helped Lift For Life take off at Penn State. He is shown here in 2005, the third year of the event.

Joe Rokita

then referred us to industry professionals who could help. This was turning into something special almost overnight.

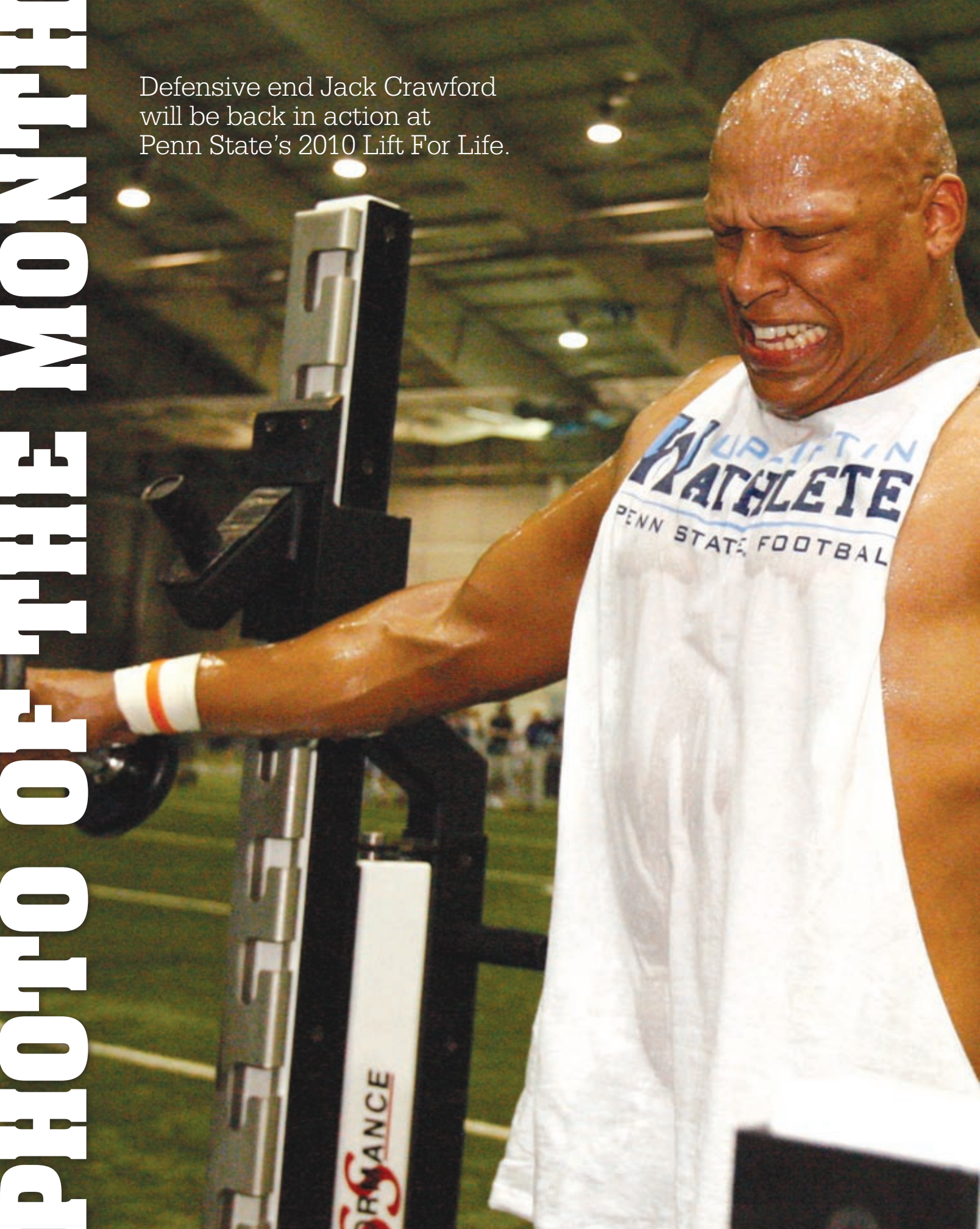
My dad was recovering as expected, too. He was jogging before he was supposed to be able to walk. He watched me play my final Blue-White Game that spring. After the game, Mark Brennan, then of Blue White Illustrated, approached me in the media room to ask about this Lift For Life he had heard rumors about. We still didn't have a great plan — just a cool idea. Apparently, it was cool enough to make his next column. And cool enough that we received our first donation from Carlton and Sandy Miller. If we weren't committed before, we were now. There was no turning back.

The first annual Lift For Life took place in July 2003. About half of our team voluntarily signed up for one of strength coach John Thomas' toughest workouts imaginable. A handful of friends,

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PHOTO OF THE MONTH

Defensive end Jack Crawford will be back in action at Penn State's 2010 Lift For Life.



UPLIFTING ATHLETES' EVENTS

- | | |
|--------------------|---|
| March 26 | Colgate Lift For Life |
| April 23-24 | Penn State Uplifting Athletes Dunk Tank
(Blue-White Game Carnival) |
| May 1 | Boston College Lift For Life |
| May 22 | Highmark Walk For a Healthy Community
(Harrisburg, Pa.) |
| June 14 | AmericChoice Charity Golf Classic
(Carlisle, Pa.) |
| July 9 | Penn State Lift For Life |
| July 16-17 | Rare Disease Champion Presentation
(College Football Hall of Fame, South Bend, Ind.) |
| Sept. 3 | College Colors Days |

*For more information on these events or to make a donation to Uplifting Athletes,
please visit www.upliftingathletes.org.*

The Willie family, shown with former Lion Jordan Norwood, provided more motivation for Shirley and company.



Submitted by Scott Shirley

family members and fans showed up to make their donations and show their support. The media enjoyed this rare opportunity to cover Penn State football in the middle of the summer. Our efforts raised more than \$10,000 for the Kidney Cancer Association. But more than anything, we were excited about the potential that this had in every respect.

None of this would have happened if I had not been fortunate enough to be a part of the Penn State football program. The recruiting philosophy leads to a certain type of person playing at Penn State, and consequently brought Damone, Dave and myself together. The coaches and administration trusted our abilities to do things right and believed that we could succeed on our own. The fans supported us from the beginning, and the media helped us tell our story. The inaugural Lift For Life was living proof that "Success With Honor" is more than a tagline for the athletic department. It was and is what makes me proud to be a Nittany Lion.

Our 'Aha' Moment

The following summer, the same group of guys got back to work. We were moving the event from the weight room into Holuba Hall to accommodate more fans. It was bigger and better in every way. More participants, more volunteers, more money. Kidney cancer patients were calling Deloris to share their stories and to thank us for inspiring them. We even registered Lift For Life as a student organization to provide some continuity in the program, as it was our last summer in State College. We wanted to ensure that the event would always be run by the current players so they could enjoy the same benefits.

One evening after the event, Dave and I were writing thank-you notes with the help of another volunteer, Carrie Konosky, from the Lionettes Dance Team. It was getting late, and we were

laughing about the fact that we had raised more than \$50,000 for the Kidney Cancer Association but we had never actually met anyone from the organization. We discussed going to visit its office in Chicago, but when the three of us looked at our calendars, the only weekend that we were all available started the next day. So I called the KCA's director of development and asked if staff members would be around. She said they would but sounded frantic and asked if she could call back. Meanwhile, we all called our parents to let them know we were heading to Chicago. When the KCA called back, we were told the organization was holding its biggest patient conference of the year. We thought it was perfect, but

staff members were afraid they wouldn't get to spend any quality time with us.

Our decision-making process continued on our way to the airport to price flights. Sure enough, last-minute airfare from State College to Chicago was not an option. Turns out that a rental car was. We took a big old Buick from the rental lot back to our apartments. Dave and I did some laundry, and we hit the road around midnight. Mapquest said it was only a 10-hour drive.

About an hour outside of Chicago, the KCA called to see if we were still coming. Fresh off a rest-stop nap in Indiana, we explained that our ETA was around noon. Our timing was perfect, because that's when the keynote speaker was scheduled to present, and he was no longer able to make it. I was asked to fill in.

I jumped in the backseat, plugged my laptop into my cell phone and started downloading some pictures to build a PowerPoint presentation. We pulled up to the curb, the valet took our car, and the three of us were ushered right up to the stage. The funny thing is, we still had not met anyone from the KCA yet.

The next five or 10 minutes were among the best of my life. We were interrupted three times by standing ovations. The audience lived in the same world that I did — a world in which people tell them as a statement of fact that nothing can be done. Well guess what? We are Penn State and we are doing something. The medical advisory board was moved to tears. They dedicated their careers to a disease that was respected by few. They were no longer alone. We were treated like rock stars the rest of the weekend. Children of the patients wrote us thank-you letters because their parents were inspired with courage, spirit and hope. Our effort was always bigger than me and my father, but this was the first time that I realized just how big it was.

We had an obligation to help it reach its full potential.

The Evolution of Uplifting Athletes

A few months later, I started exchanging e-mails with a new donor named David Wozniak. The first message he sent me was actually a thank you for an autographed item he won as a door prize. Through conversation, I learned that Dave had a wealth of experience in branding and advertising. He saw the same potential that we did in all of the facets of our effort and felt compelled to help. At the time, we were trying to promote an eBay auction for an autographed football donated by John Cappelletti. Dave's insight made a big difference, and working with him was energizing.

My dad watched me graduate — this time with a master's degree — in December 2004. We transitioned the leadership of our student organization to members of the next class on the football team, and I moved to Washington, D.C., to work as an engineer at Clark Construction Company. Dave Wozniak rolled up his sleeves and helped by mentoring the group that was left in charge. He acquired an intimate understanding of our program, and our third Lift For Life — in 2005 — set a new standard for participation, attendance,

similar challenges living in a world of isolation. The idea of creating an organization that could effectively use college football as a platform to make rare diseases a national priority seemed daunting. But the challenge was exciting, too.

In the midst of all this, my father's cancer came back with a vengeance later that summer. It was difficult for me because I had just started my dream job and was trying to continue to grow our efforts to fund kidney cancer research, but we were running out of time. There were literally not enough hours in the day. The cancer eventually took my father, but it never beat him. What we learned from his fight inspired a movement that will change the world for people in similar situations.

All 30 million of them.

I had always said that this was bigger than him. When he passed away on Oct. 17, 2005, that became the new reality for everyone else who had joined us in our fight.

Over the course of the next year, Dave Wozniak and I spent most of our free time working together, researching, writing and



Unlike most other athletic departments, the folks at Colgate quickly embraced Uplifting Athletes.

Submitted by Scott Shirley

media coverage and fundraising.

The more we talked about Lift For Life, the deeper we got into the strategy. We had always had a grand vision for how big this could be. As college kids, it's pretty easy to dream. Making dreams a reality takes some planning, though. And that's where Dave excelled. We discussed the fact that kidney cancer was one of nearly 7,000 rare diseases and that all 30 million rare disease patients face

editing a business plan that would evolve our organization and see us through the critical next steps. It had to be a coordinated effort. The brand had to be strong. This was no longer just a lifting competition. Uplifting Athletes was the name agreed upon for what our effort had become. Our mission was to align college football with rare diseases and elevate them as a national priority. The chapters would be run by current football student-athletes, and

At Boston College, the team rallied around Herzlich. The rest of the ACC followed suit, as Herzlich is shown here accepting a check from his peers at Virginia Tech.



Submitted by Scott Shirley

they would benefit rare disease causes relevant to their teams.

We developed an expansion strategy that was focused on a controlled growth starting with high-profile schools. Penn State became recognized as the first official chapter of Uplifting Athletes, and the group experienced another successful year. On the heels of another great Lift For Life event in State College in 2006, we published our business plan. The time had come to start recruiting new schools. I was still working full-time at Clark, and Dave had a full-time job in Philadelphia, so our sales calls were limited to phone, e-mail or weekends. It proved to be much more difficult than expected, but we made inroads with two of the biggest football programs in the country. Yet Penn State remained our lone chapter in 2007.

A No-Risk Decision

After the Penn State chapter's Lift For Life that year, I got an e-mail from Carol Willie in Oregon. She thanked me for bringing attention to kidney cancer, because both her husband and her father were kidney cancer patients. She went on to tell me that her and

her husband had taken their kids, 12-year-old Alison and 7-year-old Eric, cross-country to lobby on Capitol Hill, and they were surprised by what they learned. One of the staffers they met was shocked that the newest drug was not being covered by insurance ... until they told him it was for kidney cancer. The staffer quickly explained that it was not a "popular cancer." Eric offered the staffer a green bracelet (for kidney cancer) before they left, but the staffer politely declined, stating that they could not accept gifts.

Our mission never seemed more clear. There was a need for what we were trying to do. But the new schools that we were working with could not see past the promotional value of an event like Lift For Life. And if it was just a promotional event, they felt like their marketing staffs could do a better job organizing it than the student-athletes. They finally concluded that they could attract more fans by benefitting more-popular causes. I felt totally helpless. My hands were tied by my daily obligations to my job — a job that I thoroughly enjoyed for a company that I loved. But if we didn't do

something fast, other schools were going to be doing similar events for different causes and our mission would be lost.

In August 2007, I called one of my best friends, who worked in Clark's human resources department, and asked if we could talk. It was like a scene from a movie. We met outside by the monuments and had a heart-to-heart conversation about everything that had transpired. I feared that I would be letting the company down if I left. Even worse, I would be letting her down, since she had personally recruited me to work there. It seemed pretty simple to her, though. It was a no-risk decision. Clark was going to be fine, and so was I. Regardless of the outcome, the learning experience and the networking opportunities were going to help me more in the end. I submitted my two-weeks' notice the next day, packed my bags and got out of town. Clark even made a nice contribution to help me get started.

Humble (New) Beginnings

As low-risk as the decision was on paper, I didn't account for the impact on my lifestyle. I went from living my dream to moving

back in with my mom at age 27. The hours that I worked were around the clock. Every decision that I made in my personal life was, and still is, based on what's best for the organization. I'm on the road more than I'm home.

Our budget was so small that convenience was never a factor in my travel. I would drive up to six hours for meetings, book early or late flights, sleep on friends' couches, take public transportation, work in public libraries, wear hand-me-downs and eat leftovers. My income was cut to about a third, and I had to do my own fundraising to make sure that I could even get paid. All of this has taken a toll on my friendships and relationships. Even though I'm trying to do what everyone considers a good thing.

We started to see progress, but not necessarily in ways that we expected. The medical community embraced us. The football community remained suspicious. I was learning what a tough business both sports and nonprofits could be. Whether either of us knew it or not, we were competing for donations with organizations like the American Cancer Society and the Lance Armstrong Foundation. However, we were serving a unique population — the rare disease community. And we were taking a public relations approach to what many had approached as a scientific problem. Within months, I found myself as a guest at an international consortium on rare diseases. Yet I couldn't get a football coach to call me back.

The 2008 summer had rolled around, and Penn State stood alone again in terms of staging the Lift For Life competition. I went to Dallas in June to attend the NACDA (National Association of Collegiate Directors of Athletics) Convention. While I was there,



It was clear things were taking off when Florida State pitched in to help Boston College's Uplifting Athletes' effort, too.

Submitted by Scott Shirley

I invited Colgate University's athletic director, David Roach, to breakfast so we could discuss our challenges with expansion. He suggested that I take a trip to Hamilton, N.Y., when I returned from



Brett Brackett (left) is the latest Nittany Lion to preside over Penn State's chapter of Uplifting Athletes. But many other schools were initially reluctant to allow student-athletes to have complete control over such a wide-ranging endeavor.

Penn State Uplifting Athletes

Shirley's office in Camp Hill, Pa., is filled with reminders of the positive work Uplifting Athletes has done.



Harvey Levine

the convention and meet with a small group of his players. A long flight and a short four-hour drive later, I met with the players in a coffee shop and gave them the same presentation I had given every other school that year.

By the time I got home, their captain had e-mailed me to let me know that they did everything that we required to start a chapter.

Everything! In the four hours it took me to drive home. I hadn't been able to get that far with any other school in the previous 10 months. The momentum soon brought along chapters at Ohio State and Maryland that had been in the works.

Former Penn State and NFL tight end Mickey Shuler donated some office space for me to use as I built our team. We expanded our mission to include more-traditional service programs, such as advocacy, education, outreach and research. I met kidney cancer

patients who were surviving on one of the new treatments that had been brought to market since we started our effort in 2003 (now totaling six — Nexavar, Sutent, Torisel, Afinitor, Avastin, Votrient). Things seemed to be going pretty well. Then the bad economy caught up to me.

During the first three months of 2009, the organization didn't have enough money to pay me. Our board considered laying me off because unemployment would have actually been worth more than my salary in the first place. Fortunately, things started to fall back into place before we had to exercise that option. Then in May, Dave Wozniak forwarded me a headline from ESPN.com about Boston College linebacker Mark Herzlich being diagnosed with Ewing's sarcoma.

Brett Brackett, the current president of the Penn State chapter, offered to reach out to Ryan Lindsey, a Boston College wide receiver

Brett had met in a high school all-star game. As fate would have it, Ryan had been at Penn State for Global Rare Disease Day, so he was already familiar with Uplifting Athletes. He quickly rallied his teammates around Mark, much as my teammates had done for me. They raised more than \$30,000 in 30 days with their inaugural Lift For Life. The best part might have been when their strength coach came up to me immediately after their event and told me that Ryan was probably the last guy they would have picked to do something like this. Uplifting Athletes gave him a sense of purpose and direction, helping him mature overnight.

True Leadership

Bill Curry, the longtime coach whose stops included Georgia Tech, Alabama, Kentucky and Georgia State, once told me that true leadership is made up of the unexpected, undeserving, selfless acts of kindness that people cannot deny. Boston College went down to Clemson during the third week of the 2009 season. Before the game, Clemson's head coach handed Mark Herzlich a \$5,000 donation to Boston College's chapter of Uplifting Athletes. He didn't make a big deal out of it; he just wanted to help the cause. A few local newspapers picked up the story, and my phone started ringing off the hook.

Virginia Tech wanted to do something to help, so the players on its scout team sold wristbands during a home game to raise money for Uplifting Athletes. Then Florida State presented a check to Uplifting Athletes when "ESPN Gameday" visited Boston College.

The following week, North Carolina State players donated their meal money to start a campus-wide fundraising campaign. Players at the University of Virginia worked with their student government to create the 'Hoos for Herzlich campaign. The Orange Bowl Committee, Lott Trophy, ACC Officials and Charlie Weis all made donations throughout the season, too. All inspired by a truly selfless act.

The Future

On one of my school visits, I was given a copy of Wendy Kopp's book titled "One Day All Children..." The story provides detailed insight into the challenges she's faced as founder and CEO of Teach For America. With the turn of every page, I was able to relate to her experiences. It reads almost like a blueprint to me. But it reinforces the point that we still have a long way to go. The good news is that I know how her book ended and that the road was not paved for her, either.

We are making a difference — a big difference.

In the lives of 30 million patients with rare diseases. In the lives of the college football players who buy into our program. And in the world where these guys will be our future leaders.

Uplifting Athletes will continue to expand to other college football programs. We will continue to invest in promising rare disease research. And we will continue to inspire with courage, spirit and hope.

The words we live by ring as true now as they ever have: Together...We Are...Stronger! ■

Scott Shirley was a walk-on receiver for the Nittany Lions who lettered as a senior in 2003. For more on what Uplifting Athletes is doing at schools across the nation, visit UpliftingAthletes.org.

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