

From: Southern Arizona AOG soazaogpresident@gmail.com
Subject: November Newsletter
Date: November 22, 2019 at 11:10 AM
To: Southern Arizona AOG soazaogpresident@gmail.com

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SOUTHERN ARIZONA CHAPTER

UNITED STATES AIR FORCE ACADEMY

Happy Thanksgiving!

Hello Southern Arizona AOG,

It's that time of year, when you get to relive the excitement of being a fourth classman and seeing the Zoo in the rearview mirror as you headed home for the first time since showing up for BCT. I hope that you have similarly exciting plans for Thanksgiving this year.

Here in Southern Arizona, there are a couple of events coming up in December that you might be interested in:

- **Saturday, 14 Dec: Walk for Primary Immune Deficiency Foundation.** Randy Cumberworth ('90) and his wife Liana have organized this walk as a fundraiser for IDF. Please [click here](#) for details of the event itself and for how you can donate. Randy's unabridged story is cut and pasted below.
- **Saturday, 28 Dec: All-Academies Ball.** This event has been a Parents' Club staple for many years. For the event, cadets from all of the Academies bring their mess dress (or service dress if they haven't been issued mess dress yet) home for the holidays. For the big night, they, together with their families and guests, dress up and meet at a location in the Phoenix area for a dining-out with all the trimmings. As you've seen in the recent past, the AOG and the Parents' Clubs are making an effort to

In the recent past, the AOG and the Parents' Clubs are making an effort to combine forces to take advantage of economies of scale. To that end, this is the first time the AOG has been invited to the All-Academies Ball. The 28th is just far enough away for you to lose a couple of pounds so you can fit into the mess dress that's been hanging in your closet for all these years! Event details are included below following information about the IDF walk. It's directly cut and pasted from the organizers' e-mails.

In January, in accordance with the chapter bylaws, we'll be electing new board members at the annual business meeting. This is your chance to have a say in where we place our focus in the coming year. In particular, we're looking for some creative and industrious souls to serve on the Founder's Day committee to create a memorable event this April. Details of the business meeting will be included in the December newsletter.

Speaking of, if you have something interesting and valuable to add to the conversation, please let us know. Newsletter guest commentary is welcome.

As always, please reach out if you have any great ideas for what our chapter could be doing to help grads, cadets, the Academy, and our local Southern Arizona communities.

Until next month,

Be proud, wear the colors, and Go Air Force!

Information and background on the IDF walk from Randy Cumberworth ('90):

Continue scrolling to the bottom for more info on the All-Academies Ball

Registration starts at 9 AM

Walk begins at 10:30

Post Walk Ceremony at 11:15

There will be food, fun, and even a band. Feel free to enter the walk, support one of the many participating team, or simply support this worthy cause.

Lecturer Lions and my daughters, Geneva, Alina, and Julia, participated in the

Last year, Liana and my daughters, Sonora, Alina, and Jouie, participated in the Los Angeles Immune Deficiency Foundation (IDF) Walk for Primary Immunodeficiency (PID). This year, we are both planning and hosting the first Annual IDF walk here in Tucson (www.walkforpi.org/Tucson).

Many of you know or have heard somewhat what has happened to our family over the past few years. I know all of us when we see sick or suffering children on TV or elsewhere you can't help but feel empathy. Like most of you I always felt a strong sense of empathy towards them, but it is completely different when it happens to your own family. The IDF walk for PID we are hosting is dedicated to raising money and awareness to help improve the diagnosis, treatment and quality of life of persons with primary immunodeficiencies. Below I've posted a short summary of what happened to our family, how it has changed our lives, and what is currently required for our treatment.

In May of 2010 I retired from the Air Force from Misawa AB Japan. It is somewhat strange retiring and moving on especially after living the past 7 and a half years overseas. We chose Tucson because that's where Liana and I had met and Liana was fortunate enough to be offered a job at the University of Arizona, while I was set to hang up my flight suit to become Mr. Mom for our children who were ages 6, 4, and 2 at the time.

Less than 2 weeks after we arrived in Tucson, I had a fairly severe stomach ache that had lasted over a week. I attempted to see a doctor, but it was nearly impossible due to the strange status of being on terminal leave. Finally in the middle of the night it got so bad I woke Liana and went to the ER for how bad the pain was. It turned out that it was my appendix. It had "leaked" instead of the normal appendicitis presentation. During the surgery it was found that the leak had caused gangrene to spread throughout my abdomen and it suddenly it had become life threatening. The treatment required cutting a much larger section than normal and leaving the wound open to be cleaned and packed twice a day with wet wound gel to cover the wound. Liana trained with the medical staff so that she would be able to do this at home for me instead of having to be an inpatient in the hospital. After 3 months it seemed like things were going my way. I was up and around and the last part of the wound would be closed in a week or so. That's when things really went downhill.

Less than a week from when I expected to get the O.K. from the doctor that I was finally healed, I awoke in more pain than I thought humanly possible. Every joint in my body was swollen and inflamed from the little joints in my fingers, hands, toes and feet, to my knees, shoulders and hips, to even my jaw making it difficult to talk and unable to eat solid foods. I went to the ER and they were unable to give a diagnosis. It appeared to be Rheumatoid Arthritis, but it normally didn't present itself this way. It was as if I had it for years and had let it go completely untreated. They treated me for weeks with high doses of cortical steroids which returned me to feeling normal. But within a week off of the steroids the pain and stiffness began to return. Within the next year I went from needing a cane, to a walker, going as far as needing an electrical wheelchair at times. I spent my weeks with often 2 to 3 doctor appointments going to several different specialists. I went to several specialists and pushed to have my consult sent to hospitals such as the Mayo Clinic. About 6 months after it had started, I began to have different organs fail. I started to require multiple different hormone replacement therapies. Despite seeing dozens of specialists, no one could find a reason. After a year they began listing me as having serum negative Rheumatoid Arthritis, and Lupus. Additionally I started to become routinely ill. I almost always had some sort of a cold, and was encountering pneumonia more than once a month. Finally one of the doctors made a discovery that my antibodies were extremely low. They ran some further tests and determined that I could not make most of the primary antibodies that the immune system uses anymore. I began treatment with high doses of Immunoglobulin. (Immunoglobulin is a blood product where the antibodies are filtered out of blood and blood plasma donations. A quick note it takes approximately 130 plasma donations per year to make the Immunoglobulin one person alone need for treatment. That's over 500 blood donations required for me and the girls so please give blood and plasma). This helped stabilize me and while I was in severe constant pain all the time, I was able to get out of bed for a couple hours every couple days or so.

As you can imagine this took an incredible toll on our family. Not only could I not work, but instead of me taking care of my young kids, often they had to take care of me. It was hardest on Liana who was working and trying to keep up with all my needs. Unfortunately the worst was yet to come. Sonora, Alina, and Joule, like myself, had fairly normal healthy childhoods. But in the fall of 2016,

the entire family contracted a severe viral flu. After weeks of being sick, the three girls never fully recovered. They started complaining of headaches, joint pain, and fatigue so bad they at first could no longer go to school, then they could not get up off the couch to do anything, Finally they could more often than not, not get out of bed. We began taking them to specialists. For the next two years we again went through the same set of tests I had faced while they continued to grow sicker and worse. We had suspected that my illness may have a genetic component, because both my sister and my mother had symptoms similar to mine and theirs. You cannot imagine the frustration of having your kids too sick to even get out of bed, the anger you can have towards doctors that telling you it must be psychological because their blood tests aren't showing anything or to have the doctors simply refuse to run tests that may show something simply because because your insurance company refused to pay for it (even though you are offering to pay for the test out of pocket). Or finally the fear you can have when you receive warnings from the school and the city stating that you could be investigated by Child Protective Services because of the number of absences your children are accumulating without a medical excuse because the doctors are unable to determine a definitive diagnosis. We finally removed them from school on a "Religious Waiver" to continue to home-school them ourselves as best possible while continuing to research what was wrong with them.

We finally received a break in 2017. Liana had sent a summary of my medical records into a study being conducted by the National Institute of Health. They were interested in the possible genetic link of my disease to my sister's and my mother's. After running multiple genetic tests, each more in depth, one of the top Geneticists in the world took me in a research subject. They found there were two possible genes that were likely to be the cause of my disease. One was fairly well known, while the other was completely new. There was only one other case in the world that they knew there was a mutation in this gene, but my mutation was different from theirs. The NIH fortunately picked up the girls as patients as well and have determined that all three contain the same genetic mutation that I have. Additionally we have found a new Pediatrician Immunologist that determined the girls needed immunoglobulin therapy as well. The immunoglobulin therapy helped tremendously. While it in no way was a cure, it did allow the girls to begin to have the energy to some days get out of bed. One of our girls has been able to return to school nearly full time another

... One of our girls has been able to return to school nearly full time, another part time, and one receives at home tutoring from the school district.

While Liana deserves the most credit for getting the girls and myself to where we are today, the girls themselves have shown an inner strength I never thought possible, and they continue to do so day after day. I was devastated to find out that I would be in such severe chronic pain for the rest of my life, but it was indescribable to find out that all three of my kids had the same underlying issue, and worse instead of coming out of remission at the age of 40, they had all developed their symptoms in their early teens, and would be fighting with it for the rest of their lives.

Fortunately there is hope. Though grants to organizations like the NIH, and private fundraising such as the IDF walk, fascinating research that seems almost out of science fiction is taking place. Currently at the NIH they have taken the mutated immune gene from my blood, cloned it and graphed it onto the DNA of mice currently under study in a laboratory. While still in the very early stages of testing, the hope is that they will discover how the mutation affects the immune system, and develop new drugs and treatments that may present a new treatment. While I can't be up more than a hour or two a day, I don't consider myself completely bedridden anymore. In 2017 a new drug based on genetic sequencing was passed by the FDA. It blocks one of the many channels of inflammation that my disease seems to use primarily, so I am more functional today than I have been in the last 5 years.

I want to thank all those that that helped our team from Tucson be the third biggest fundraising team at the National LA IDF walk last year. I want to once again thank those that have donated in the past and apologize for not thanking our donors personally, but my new drug makes me more susceptible to infection and I have been in and out of the hospital quite often and it fell out of my cross check.

Information about the All-Academies Ball from Col Matthew Towers:

1 March 2019

Dear Sir or Madam:

Dear Sir or Madam:

I am Colonel Matthew Towers, and I am proud to serve in the Air Force Academy Parents' Club of Arizona. In conjunction with the other U.S. military academies, we rotate hosting duties for the annual All Academies Military Ball which honors and recognizes the cadets and midshipmen of all five service academies from Arizona. It is a tradition celebrated across America and an important part of community support for those in uniform. We are asking for your support for this noble event.

The mission of our five service academies (Air Force Academy, West Point, Naval Academy, Coast Guard Academy, and Merchant Marine Academy) is to educate, train and inspire future leaders to a lifetime of service to our nation, both in and out of uniform.

This year, the Air Force Academy Parents' Club will be hosting the Arizona All Academies Military Ball. It will be held on Saturday, December 28, 2019 at the Renaissance Phoenix Downtown. Typically 400-450 cadets, midshipmen, family, and community members attend this wonderful evening full of military tradition and pageantry, fun and festivity. The event also serves as a congratulatory farewell for those cadets and midshipmen who will be commissioned in May, 2020 to begin their careers in military service to our country.

The Arizona All Academies Military Ball is not a fundraising event. All donations go directly to defray total expenses associated with honoring our cadets and midshipmen. We do our best to keep costs down for everyone involved, and the associated parents clubs host our cadets/midshipmen and their dates. We are very proud of these talented and dedicated young men and women and believe that you will be too. We invite you to meet them, and their families, on 28 December 2019. We believe that you will walk away with a renewed faith in the future of our military and our nation. If you are unable to attend, please consider a financial contribution to help us to offset some of the costs.

The levels of sponsorship are listed on the enclosed form. Your generous sponsorship will be acknowledged during the program. Your donations may be tax deductible as our club has been designated as a non-profit, tax-exempt 501(c) 3 organization, tax ID# 86-0927515. To set up your sponsorship today, please return the attached form with your payment.

The enclosed form is a request of the parent organization of Academy cadets and midshipmen.

I thank you for your support of the next generation of America's leaders!

Sincerely,

Matt Towers

Matthew Towers

Colonel, US Air Force

Air Force Academy Parents Club of Arizona

Arizona All Academies Military Ball 2019 Sponsorships

- Cash/Gift Card/Item Donation Estimated
Value \$ _____ Description of donation or
sponsor level: _____
- Cadet Sponsor: \$150-\$499
- Academy Booster: \$500-\$999
(Includes acknowledgement in the program, logo on event signage and
presentation materials throughout the evening and 2 ball tickets)
- Lieutenant Sponsor \$1,000-\$2,499 (Limit 5 Sponsors) (Includes all
benefits listed above and 4 ball tickets)
- Colonel Sponsor \$2,500-\$4,999 (Limit 3 Sponsors)
(Includes all benefits listed above, contribution of a sponsored raffle prize,
with at \$100 minimum value, and 6 ball tickets)
- General Sponsor \$5,000+ (Limit 2 Sponsors)
(Includes all benefits listed above, 30-second video to be played during
the dinner program, 10 tickets and one room at the hotel the night of the
ball)

Make checks payable to 'USAFA Arizona Parents Club' and return to:
Mary Miller – 2019 Ball Committee, 4227 E County Down Drive, Chandler, AZ
85249 info@usafa-azparentsclub.com; 480-689-2602

Donations may also be made via PayPal on our website: www.usafa-azparentsclub.com/product-page/usafa-arizona-parent-s-club-academy-dues

**More information on the All-Academies Ball from Mary Miller of the
Arizona Parents' Club:**

Arizona USAFA & AOG Families -

By now, you should have received your invitations for the All Academies Ball in the mail. We're so excited to see you all there!

Check out these pictures from last year: <https://picsinpix.smugmug.com/2018-All-Academies-Ball/n-NWVVXZ/>

You can register RSVP using the card in the invitation or online here: <https://www.usafa-azparentsclub.com/events-1/2019-all-academies-ball>

You can also reserve your hotel room at the discounted group rate of \$99/night (plus tax) when you call 1-800-309-8138 and ask for "The United States Air Force AZ Parents Dinner" room rate or book online here: <https://book.passkey.com/event/49911968/owner/2302/home>

Don't forget - the Ball ticket rate is \$75/per person until December 1st, and then goes up to \$100/per person. AZ Cadets are covered for members current on dues.

Also, **please continue to request donations (letter attached)** and we encourage you to send gift cards for the Cadets that each Cadet and Midshipmen will receive. You can either donate online or mail gift cards directly to:

USAFA AZ Parents Club
Attn: Mary Miller
4227 E. County Down Drive
Chandler AZ 85249

Thanks so much to all of you who have already sent cards and donations!
We are making great progress; let's make this year's event better than ever!

GO FALCONS!!
Mary



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