Rare Disease Club

When and why was your club formed?
Rare Disease Club (RD) was founded by two students, Anderson Van and Caroline Kim of the Keck Graduate Institute (KGI) School of Pharmacy in February 2015. The goal of the club is to focus on spreading awareness of rare diseases, providing education, establishing professional relationships and partnerships, and promoting career opportunities that align with rare diseases.

What are your primary activities?
We hold monthly general meetings and monthly executive board meetings. During our general meetings we have educational activities within, including Rare Disease of the Day where RDC members present on a different rare disease each time.
Our big events during the year includes:
1. Rare Disease Poster Day
2. NORD Day
3. Rare Disease Club & WeHealth Paint Nite
4. Holiday socials & fundraisers

What does it mean to become more involved with the rare disease community?
The biggest reward is knowing that we are improving the quality of lives for patients with rare disorders and their families. It’s truly motivating to see students who have not heard of rare diseases before to students who actively spreads awareness of rare diseases to the public. Our reward comes from even spreading awareness of one disease - because that just means we are one step closer in making rare diseases un-rare.

Why do you want to be affiliated with NORD?
Partnering with NORD has given our club the biggest boost ever since our establishment of our club. In fact, KGI’s President Schuster, who is a board member of NORD, was one of greatest supporting factor to our success.

RDC views NORD as a role model in all the ways that NORD continues to improves the lives of rare disease patients. Following footsteps of NORD and even having the opportunity to call NORD as our mentor organization has guided RDC in gearing towards the right direction in the rare disease community. Now, with an even stronger partnership between RDC and NORD, RDC benefits from access to rare disease resources not only from Southern California, but now nationwide. Our club now has the capability of holding collaborative events with NORD coast to coast.

RDC is also requiring that all of our members register for NORD’s student program as well, which allows our members to have more opportunities to participate in NORD advocacy and educational events.

NORD has helped our club with our events held on campus at KGI also by providing us with guest speakers, educational tools, and has helped RDC become more recognized. As a club, we strongly believe that our partnership benefits not only RDC and NORD but more importantly, our partnership benefits the rare disease community.
How will this club impact your future career?
Anderson:
The club has impacted me by helping me identify that I envision myself becoming a pharmacist with the endeavors of holding a position in the pharmaceutical industry who will specialize in rare disease drugs (orphan drugs). My concentration in my current pharmacy curriculum, Clinical Trials and Regulatory Affairs, will allow me to discover how I can play a role in improving the number of FDA approved treatments for rare disorders. RDC and NORD has given me the knowledge of what treatments are or are not currently available, and has also built me a strong network foundation for where I hope to be in the future linking Pharmacy with Rare Diseases.

Caroline:
Recognition of the rare diseases has motivated me to make significant impact in the community. Coming from a personal background of having a rare disease, I understand the struggles and the life changes that follow with the disease. Now with a better view of the rare disease community with a health care professional perspective, I realized more that there are still huge gaps to address clinically. As a pharmacy student, I realized that there isn’t a specific field for pharmacist who manages medications for rare disease patients. The patients could be taking countless of medication for their condition without completely knowing how the medications could affect their current condition, comorbidities, and other medications that they could be taking. My goal is to address full medication management service to all the rare disease patients and provide competent and reliable clinical information on each medications. Knowing that there are many struggles in fighting with unanswered questions, I want to guide the patients in hopes to give reliable answered on how the medication will help the patients - I believe this is one thing I can do to help the community.