THE DOSE

Official Newsletter of UAEM North America



A Letter from the Editors

BY THE DOSE EDITORS

The voice is an important and powerful tool that each rising leader can practice using as a form of individual self-expression, ultimately helping to promote growth and drive positive change in our world.

The Dose, Universities Allied for Essential Medicines (UAEM) North America's Official Newsletter, is committed to encouraging and supporting the use of journalism to empower students; enhance writing skills, publishing creativity, responsibility, and accountability; and engage, educate, and enrich current UAEM members as well as those belonging to UAEM-affiliated institutions by reporting on activities and events surrounding the access to medicines movement taking place in our global, interconnected, multi-university community.

We, as the editors of The Dose, are passionate about establishing a collaborative platform that embraces individual self-expression and embodies UAEM's core principles of equity and transparency. Thank you to the amazing and hard-working team of student activists in UAEM and beyond who make tireless efforts to combat injustice and advance global health through teambased projects, campaigns, and advocacy work.

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Transforming Drug Pricing in the UC System with the AAP

BY ADITI MALHOTRA AND MEGAN CURTIN

As members of UAEM UC Berkeley, we understand not only the power of Berkeley research innovation, but also our role as students to defend access to these publicly-funded therapies. Over the last two years, we have been investigating our university's access-based licensing called the <u>Socially Responsible Licensing</u> <u>Program</u> (SRLP). The program began in 2003 with the goal of ensuring access to Berkeley therapies for neglected diseases in low-and-middle-income countries (LMICs). However, there are no examples of therapies supported by the program within the last decade. Through conversations with the UC Berkeley Innovative Genomics Institute (IGI), it has become clear that there is a growing need for improved licensing that supports greater accessibility levels. A new sickle cell therapy with promising results being developed at the IGI is expected to cost \$2 million per patient, a price that presents a large barrier for most people in need of treatment. We soon learned that the solution to the limitations in Berkeley's licensing practices could be found by exploring foundational work achieved by the UAEM team at UCLA.



UAEM UC Berkeley organizing student events on campus, 2022

UCLA developed Xtandi, a publicly-funded, life-saving prostate cancer drug that has cost Medicare <u>\$5.8 billion</u> from 2012 through 2019. UAEM UCLA's student-driven activism was able to improve access to and affordability of generically manufactured Xtandi, and UAEM UCLA extended their efforts by creating a set of guidelines that would ensure access to future therapies, called the Affordable Access Plan (AAP). The AAP would require licensees to develop a preemptive plan for how they intend to commercialize their product and ensure that prices would be at or below market value.

We knew our ambitious goal of universal implementation of the AAP in the UC system had to be met with action. In the Fall of 2022, our UAEM team at UC Berkeley organized a campaign for the adoption of the AAP. We organized a promising meeting regarding the implementation of the AAP and the expansion of our existing SRLP with Chancellor Carol Christ. Following the footsteps of our UAEM UCLA student advocates who defended patient access to Xtandi at a UC Board of Regents meeting, our chapter went to the UCSF Regents meeting in November and urged the Board to consider the adoption of the AAP across all UC institutions as universal licensing language to prevent future therapies from being inaccessible.

Transforming Drug Pricing in the UC System with the AAP (cont.)

BY ADITI MALHOTRA AND MEGAN CURTIN

We soon found that for a movement to be successful, it requires strength in community. A great contribution to our meeting was the echoed support provided by genetics professor and founder of the open-access Public Library of Science, Dr. Michael Eisen. UAEM UC Berkeley also got an opportunity to host this year's annual UAEM North American Conference, where Dr. Dave A. Chokshi, a distinguished UAEM alum and physician who helped lead New York City's public health response to the pandemic, gave a presentation as our keynote speaker. With his leadership in mind, we were inspired to expand the scope of our mission beyond UC Berkeley and work towards achieving a universal adoption of the AAP across all schools in the University of California system. We created a <u>petition</u> that has since gained support from many Berkeley faculty, including Dr. Eva Harris, who initially prompted the creation of Berkeley's existing SRLP. Our UAEM UC Berkeley team also wrote a resolution in support of the adoption of the AAP with collaborative efforts from our undergraduate student association, and we are currently working on writing a similar resolution with our graduate student association to demonstrate a united front of students across our campus.



From left to right, Li Teh (Publicity Executive), Mye Makornwattana (Legislative Executive), Aditi Malhotra (Vice President), and Leon Zhao (President) elected to serve as the rising chapter leadership board at UAEM UC Berkeley for the 2023-2024 academic year

UAEM UC Berkeley members Diego De Nault (left) and Allisun Wiltshire (right) tabling for member recruitment and increasing awareness for the AAP petition

On January 7th, the UC Student Association, a panel of student representatives from all nine UC campuses, passed the joint resolution written by UAEM UC Berkeley in support of the universal adoption of the AAP. Looking ahead, we will continue our conversations with UC Berkeley administration and work with other UC students to support each campus in implementing access-based licensing through the AAP. For other UAEM chapters looking to make a difference in the way therapeutic licensing and affordable health technologies are negotiated at their institutions, it might be encouraging to find allies in faculty and other student groups who share the same ideals.

A key component to the campaign at Berkeley and UCLA has also been raising awareness of our respective university's actions. This could be achieved through writing an op-ed in your school paper or contacting local news. While our mission may be challenging, sustainable and consistent efforts by students and universities alike are part of the solution to the access to medicines crisis. Whether these efforts be joining an organization like UAEM, signing a petition (consider signing our petition for the Affordable Access Plan) or staging a protest; they all add up to same goal: putting people before profit.

(Un)gatekeeping the Cure

BY ZAINAB JAMALI

A true pharmaceutical 'Robin Hood,' Dr. Yusuf Hamied is known for his essential work in reverse-engineering key medicines to make them more affordable and accessible. His company, Cipla, was instrumental in the early movement to treat the HIV/AIDS epidemic in lower and middle-income countries (LMICs) as seen in the 2013 documentary *Fire in the Blood*. At the European Commission on AIDS in 2000, Dr. Hamied offered to supply antiretroviral therapies (ARTs) at less than a tenth of their standing price. Hamied's Cipla was the first company to try directly infiltrating the pharmaceutical cartel and publicly offer their generic antiretroviral at a small fraction of the brand name price. Although major pharmaceutical companies consider reverse-engineered drug products as pirated ones, there is no question that this method effectively makes medicines affordable for vulnerable populations bearing the greatest burden of disease.

When HIV first became a major focus of pharmaceutical research, ensuring accessibility to treatment was a distant idea in comparison to achieving availability. The first antiretroviral medication for HIV, called azidothymidine, was made available for treatment in 1987, but the first wave of therapies was incredibly expensive. This development mainly served to reduce the number of AIDS-related hospitalizations and deaths in the developed world. In LMICs, such therapies would be unreachable. Pfizer and other drug companies were producing new and effective formulas of antiretroviral therapies, but much like a cartel, they took advantage of the widespread need for these critical medicines and deliberately created high and extortionate prices. The countries and people who needed these therapies most urgently simply could not afford them. So, despite the existence of treatment options, AIDS was still a leading cause of death in most of the Global South.

It wasn't until the turn of the century, when people like Dr. Hamied began their reverse-engineering work, that generic versions of the drug became available on the market. Essentially, they worked to find the basic formulas of the prominent – and expensive – antiretrovirals already on the market and recreate them to create generic editions. Such efforts have been met with backlash due to claims of intellectual property infringement, but nonetheless have made immense progress in distributing these essential medicines to countries in need. Unfortunately, rigid patent laws restrict this type of work heavily and continue to keep many HIV-ridden countries away from these life-changing therapies.

This legal minefield continues to inhibit public health efforts to mediate the HIV/AIDS crisis in LMICs. According to HIV.gov, approximately 38 million people worldwide were living with HIV as of 2020. Of those, 85% knew of their status, 75% had access to antiretroviral therapies, and only 68% were virally suppressed. While this may seem like a lot statistically, it means that 5.9 million people still require access to HIV testing services and 9.7 million people are still unable to receive treatment. Additionally, HIV incidence, or the number of new cases, in 2021 was 1.5 million, which includes young children. This is alarmingly high, especially given that consistent access to antiretrovirals could eliminate new cases through viral suppression.

Despite the tireless work of advocates and continued efforts to bypass patent laws and proliferate generic treatments to populations in need, there is simply too large a global population that is still in need of prevention methods, testing, and treatment. Science is not what is holding us back from addressing this epidemic thoroughly; instead, it is societal and economically-driven institutions that are gatekeeping cures by not only working to maximize their profit on life-saving therapies that are often largely taxpayer-funded, but also by fighting against actions and legislature that could streamline widespread availability of these medicines. When utilitarian public health efforts are inhibited so severely in the name of profit, action and activism are needed to create change. This could take the form of global fieldwork in organizing and funding international testing and treatment infrastructure, protesting the harmful role that 'Big Pharma' plays in prolonging health crises, raising awareness about the history of the disease and its roots in inequity, or advocacy work on any media platform for progress.

Activists young and old have the power to follow in the footsteps of changemakers like Dr. Hamied and push for increased global medical equity for patients living with HIV/AIDS and combat the collective evil that is Big Pharma, a profit-driven entity that works to maximize financial benefits at the cost of patient lives and well-being.

A Spoonful of Sugar: Justin Mendoza, UAEM NA's Executive Director BY THE DOSE EDITORS

Question #1: How did you get involved with UAEM?

I joined UAEM in 2010, I was a pre-medical student at Central Michigan University and looking for a way to make an impact in health care. I met a UAEM student leader at a club fair, and joined the next meeting. I didn't realize until that moment that students could be part of changing the world. I heard for the first time about university research and how it was connected to the drugs people take to survive, and I learned about the way our inequitable health care systems let people die all over the world if they can't afford those medicines. I was hooked, and I went to the national conference just a few weeks later, where I really felt the energy about what could happen. Since then, I have been a chapter leader, a member of the North America Coordinating Committee, a delegate to the World Health Assembly, a member of our board of directors, and now, executive director for UAEM North America. This organization has been a part of my life for 13 years, and I wouldn't have it any other way.



Headshot of Justin Mendoza

Question #2: What is your favorite memory in UAEM?

It's easy to point to so many great memories. But one of the top ones was the science march in 2017. That year, our president, Gloria Tavera, spoke to a crowd of thousands about the importance of access to lifesaving research products developed in our labs. Her speech was great, despite the downpouring of rain that day, and honestly I remember it more than Bill Nye's speech just a couple of hours later. It was also a reunion of a number of my friends from UAEM, who I got to know over the years. To top it all off, that was the day I met my wife, Izzy, though it was after a long day of protesting and camaraderie with our community.

Question #3: What project that you worked on has been the most meaningful to you?

In my days on the UAEM North America Coordinating Committee, I jumped from project to project quite a bit. I co-led our fight against trade deals that would have kept drug prices high in countries all over the world (the Trans-Pacific Partnership and the Transatlantic Trade and Investment Partnership), I went to the World Health Assembly on our behalf and pushed for global rules that would make access to medicines easier to achieve, and I planned conferences at my university to help get people involved. I even worked on our newsletter for a couple of years! But for me, the most meaningful work always came in the form of empowerment. Whatever project I could work on, if I could help another student member or a chapter get involved and learn about what's possible, I felt like I was doing it right.

A Spoonful of Sugar: Justin Mendoza, Executive Director (cont.) BY THE DOSE EDITORS

Question #4: How have your experiences in UAEM shaped your personal and professional life?

Before UAEM, I think I would have gone to Medical school and been happy as a physician, PA, or a nurse. I was going down the clinical path and thought that was my calling. But after I discovered how much our biomedical and health care systems work against so many people worldwide, I knew I wanted to have a wider impact. UAEM led me to the field of public health, where I earned my MPH focused on health policy, and I even earned a certificate in regulatory affairs so I could learn more about how new medicines are tested and approved. I learned how to organize chapters, people around me, and eventually national campaigns, and that led me to my career as a community organizer, policy analyst, and government affairs professional. Finally, UAEM taught me the importance of grassroots fundraising and building relationships, and also the importance of sticking to the policies and priorities that are best for those around me, which drove me later to run for public office. Lessons learned from UAEM have been pivotal to every part of my career, and it's exciting to see our next set of leaders on their own paths spurred and supported by UAEM.



RFUELOR REMAILERAN ELTATS-UNIS D'AMERIQUE

UAEM Board Member Ali Greenberg (left), former UAEM Board President Gloria Tavera (middle), and UAEM NA's Executive Director Justin Mendoza (right) protesting outside the National Institutes of Health (NIH)

Justin at the World Health Assembly, 2014

Question #5: How do you envision UAEM making a difference in this world?

UAEM has strived to change the world through better policy and better examples. Our universities develop groundbreaking medicine every single year, and they sell the results of that medicine to the highest bidder, often with no consideration of affordability or access for the rest of us. I mean, insulin was invented in a university lab in 1921, yet it took until 2023 for just one manufacturer of it to actually make the medicine affordable for people who need it most. Unfortunately, most people in the world can't wait a century to afford their life saving medicines. But UAEM has solutions that can work for universities to change their policy, way before a profit margin is in the equation, and help ensure access to medicines for the future. We can also work to ensure cutting edge manufacturing and medicine production is no longer only done in the wealthiest countries in the world, but spread across the globe in a way that can ensure a more equitable future. By equipping our student leaders and advocating for what can be done today, we can ensure better policies now and a better world tomorrow.

A Spoonful of Sugar: Justin Mendoza, Executive Director (cont.) BY THE DOSE EDITORS

Question #6: How would you describe yourself in one word and why?

Octopus. Octopodes (my preferred plural, but you could go with octopuses as well) are adaptable to their environment, cunning, and each arm thinks independently for itself. It's the perfect symbol for a social movement has to be able to do, and a reminder of what the opponents of change have done for years. Opponents to change often have the ability to wrap their arms around institutions like universities, the halls of Congress, and even the world of philanthropy in order to spread a positive message and image while ultimately serving the role of feeding their own octopus. I like to think the same way about the movement for access to medicines, health justice, and so many other critical causes. I should note, I also have an octopus tattoo on my left forearm for this reason and because they are just so cool.



Justin and other students from Central Michigan University and University of Michigan at the UAEM Fall Conference, 2010



Justin and UAEM NA's Coordinating Committee at the UAEM North America Leadership Meeting (NALM), 2013

Question #7: What are some of your major interests outside of health justice and access to medicines?

Well, clearly octopodes. But also, I dabble in guitar, enjoy running (though I'm getting back into it after a hiatus), and do a lot of DIY home renovations. My wife and I moved to Michigan, near my family so we could make a house we fell in love with into our own. I just finished wallpapering a bathroom, installing a new vanity cabinet, and painting multiple rooms in our house.

Price Capping on Insulin After 100 Years

BY TED MALPASS

I am writing from Washington D.C. to commemorate the month of March 2023, as one for remembrance and jubilation for patients that rely on essential medicines across the United States. As a type 1 diabetic patient, I wish to express that the culmination of advocacy, research, and holistic consideration has led to a cascading series of events that will improve drug accessibility in this country for the foreseeable future.



President and Founder of the UAEM chapter for UC Santa Cruz, Ted Malpass, promoting access to medicines on the UC Global Health Day, 2022

March 18th marked a collaborative effort by the largest manufacturers of the treatments for type 1 diabetes. Following in the price-capping footsteps of two major insulin manufacturers Eli Lilly and Novo Nordisk, another international pharmaceutical manufacturer called Sanofi, decided to follow suit and cap their out-of-pocket price of insulin at \$35 per month. The hope was to see a significant reduction in financial burden for patients living with insulin-dependent chronic disease, but this new insulin pricing is severely restricted. Unfortunately, this price cap comes with the stipulation that patients must be insured with Medicare, which leaves millions of people with private insurance or without insurance left out. Although there is more work to be done, my excitement grows knowing that patient consideration is finally becoming a greater focus for both pharmaceutical manufacturers and leaders in government.

On the same day as Sanofi's announcement, March 18th would mark commitment from Governor Newsom's administration in California to create a state-funded option for all people who need insulin. Angela Hart, a correspondent for KHN reported that California announced its partnership with the generic drug manufacturer Civica to produce low-cost insulin available to all. This action is incredibly important because this program will be able to provide insulin for groups of people that may not qualify for Eli Lilly, Novo Nordisk, and Sanofi price cuts. California's insulin will be capped at \$35 for vials and \$55 for insulin pens for patients in California whether insured or not. California's intention to improve its patients financial burden paired with Civica's public position as a holistic provider of effective insulin is a step in the right direction and a momentous event in the access to medicines movement.

Price Capping on Insulin After 100 Years (cont.)

BY TED MALPASS

The reason these actions are vital is because insulin has been available for over 100 years, but it continues to be the cause of major patient frustration and tragedy with its skyrocketed costs. BBC reports that in 2019, the cost for a vial of Humalog, the brand name of insulin from Eli Lilly, was listed at \$275 for a month's supply paid at the pharmacy counter. For many people, this expensive, non-negotiable monthly cost is completely out of reach and severely limits a person's the ability to achieve the proper care and management needed to live a healthy life. In the same article, one patient explained how it would cost her \$7 million dollars to live until 70 if she bought insulin at the over-the-counter price. Many patients faced with this dilemma are forced to ration insulin or try living without it, and the risk of having to do this is life-threatening. Right Care Alliance reported that nearly 20 fellow insulin dependent diabetics passed away due to the rationing of insulin when it was not possible for them to meet the price asked for their supply of insulin. Each one of these individuals paid the highest tax for a disease that's diagnosis still has no known cause or cure.



From left to right, Ted Malpass, Leah Rilat, and Ava Brennan from UAEM UC Santa Cruz at the UC Regents meeting, petitioning for universal AAP adoption

Living as a type 1 diabetic for 22 years, I feel the tragedy of these preventable deaths in my deepest of hearts. In times where I personally could not afford my monthly prescription, I was able to get by thanks to free but often rare insulin samples in clinics, school programs, and family aid. The safety nets that have saved me are not predictably consistent, and for the tens of millions of patients across the globe, they may never be back-up options, and they should never have to be. Therefore, the reason why my work focus is in advocacy, activism, and education is to ensure that we can create a better future for the most vulnerable people and combat institutions that focus on profits rather than health, safety, and well-being.

As I work towards this mission, I am inspired to know that there is a building wave of identities and ideas from the individual to the global level who are also working to create meaningful change. This wave is now crashing against the smokescreen that has covered the drug pricing crisis with many of the processes of drug provision being pressured to offer greater transparency. In fact, during my recent participation in the Senate Committee on Finance hearing for "Pharmacy Benefit Managers and the Prescription Drug Supply Chain: Impact on Patients and Taxpayers" on March 30th, I was able to witness full committee support for making the drug pricing supply chain more straightforward and equitable. This event further helped me recognize that the movement for improved access to medicines is building at all levels of society, especially in spaces where people in positions of power can turn ideas into action.

The Wellness Corner: Updates and Events

BY THE UAEM NORTH AMERICAN COORDINATING COMMITTEE (NACC)

Updates on Active Campaigns and Committees

- The Empowerment team is focusing on chapter engagement by creating a sustainable program that will help chapters at different levels in the future.
- The Transparency team is focused on petitioning the FDA to enforce clinical trial results law more effectively while also increasing reporting of those results.
- The Report Card team is collecting data related to how universities license out their intellectual property related to health technologies, and are about to publish a new report card website. A launch with press release will be taking place on March 27, 2023.
- The TBOM/ETAF ("Take Back Our Medicines" and "Equitable Technology Access Framework") team plans to build out a research pipeline, create materials that explain ETAF and licensing, and help chapters start their own campaigns on this work.
- The Communications team is developing consistent content creation and leveraging resources on social networking platforms in order to achieve higher levels of engagement as well as stronger relationships and greater collaborative efforts with partnering institutions.



Participants at the UAEM North America Leadership Meeting (NALM), 2023



UAEM NA Coordinating Committee Member Declan Sakuls at a NALM social event, 2023

Recent Past Events

- The 2023 North America Leadership Meeting (NALM) took place in Washington, D.C. from February 24-26. During this weekend, the North America Coordinating Committee Members and Fellows dedicated time reviewing the UAEM organizational structure and planning measurable goals for each campaign.
- UAEM has been attending meetings with the University of California Board of Regents to advocate for the adoption of better licensing practices and encourage implementation of the Affordable Access Plan (AAP).
- Members of UAEM served as panelists to debunk pharma myths and discuss the AAP Movement on the podcast, "<u>Conversations with Rudy Rivera"</u> on April 8, 2023 at 7 pm EST.

Current Events

- The 2023 Global Leadership Annual Meeting (GLAM) is taking place in Berlin, Germany from April 21-23.
- UAEM NACC will be accepting applications from students interested in serving as NACC members for the upcoming academic year.

About The Dose Editorial Team

MADELINE CHUNG, MBE

Editor-in-Chief

Madeline Chung, MBE, is a bioethicist and health disparities researcher from Case Western Reserve University, conducting research on barriers to health care access for underserved and marginalized populations with the goal of producing meaningful findings that practitioners can integrate in their clinical practice to achieve more culturally-responsive care. She is currently a health sciences student and medical scribe exploring pathophysiology and clinical workflows in the Stanford University-Cleveland Clinic MOST Fellowship. She served as the DEI Chair of Hiring in the Cleveland Clinic's Center for Health Sciences Education, where she worked to ensure effective and equitable practices in health profession programs and increase the representation of diverse voices, backgrounds, and experiences across all levels of organization.





ISHIKA SETH

News Editor

Ishika is a third-year undergraduate student at UCLA studying Human Biology and Society. She participated in a California legislative advocacy project, and she has since become the National Liaison for the UCLA chapter as well as a NACC member. Currently, she is involved with the Xtandi and Affordable Access Plan (AAP) campaigns and is spearheading a campaign to bring increased transparency around UCLA's use of the Affordable Access Plan. Outside of UAEM, Ishika is investigating and innovating new models of equity and social medicine that can be incorporated into healthcare systems. She is also researching the impact of clinical telehealth interventions in reducing the risk for substance use disorders and volunteering in a pain management clinic for underserved communities in Los Angeles.

ZAINAB JAMALI

Features Editor

Zainab is studying Human Biology and Arabic at UCLA and aspires to pursue a career addressing global health inequities, with an emphasis on maternal and child health and access to medicines in the developing world. Her previous work in the field includes involvement with breast cancer and diabetes screening initiatives locally as well as in international communities, including Sri Lanka and India. Additionally, she has worked on refugee health issues as an intern at the International Rescue Committee. She is passionate about advocating for and working with marginalized communities in the healthcare sector. She is dedicated to increasing access to medical care and pharmaceuticals, both domestically and globally and is excited to be a part of UAEM's efforts to raise awareness and initiate change in this area.

