



Advocacy Agenda Workshop  
30-31 October 2017  
The Graduate Institute, Geneva, Switzerland

## Introduction

Non-communicable diseases (NCD) caused 70% of deaths and disability all over the globe. In the Philippines, it ranks as one of the highest causes of socioeconomic burden in Filipinos and their families. But if you look at what comprised NCDs, most are preventable and premature.

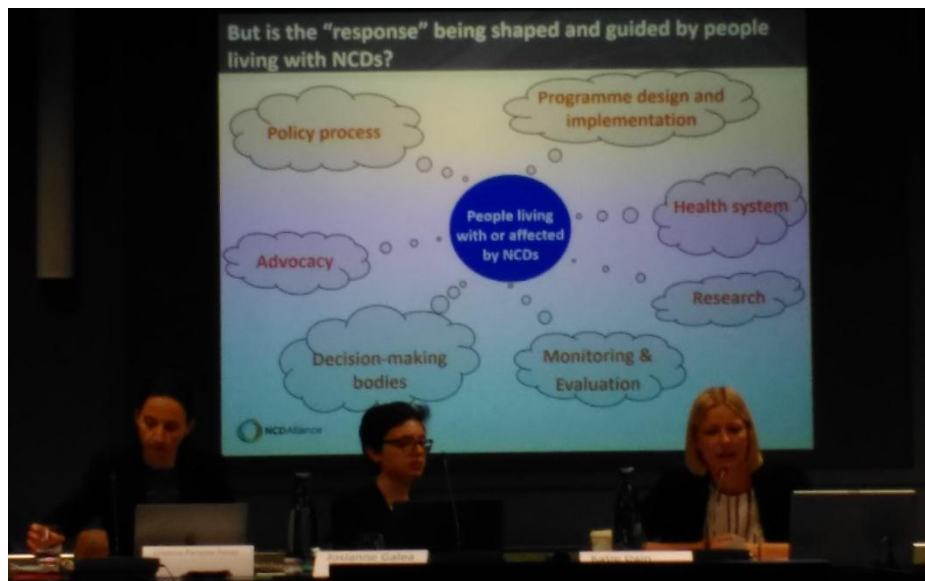
Efforts to lobby that NCD must be recognized as a global issue has been made. Meetings and dialogues with United Nations and World Health Organizations had been done in the past, made possible by civil society organizations. But what is lacking is what person/people living with NCD (PLWNCD) really is going through, what are his/her experiences, thoughts, perspectives, perceptions, struggles and triumphs. And PLWNCD is comprised of patients and care partners (family members, relatives, and friends) whose daily lives are affected.

The NCD Alliance, a global coalition that unites 2000 civil society organizations, had come up with a method to gather all of these on what they called “conversations”. From then on, “Our Views, Our Voices” (OVOV) are centered on thoughts and feelings from PLWNCDs. People around the globe were invited in order to gather their responses, either through online conversations (online survey) or community conversations (face-to-face group discussions) on what are the vital issues PLWNCDs feel essential in their health care.



## Workshop in Geneva

Our Views, Our Voices workshop held at the Graduate Institute, Geneva was attended by 34 people from 22 countries in Asia, Northern, Central and South America, Africa and Europe. The workshop focused on organizing the collective theme from the responses that resulted from the conversations, in order to have a powerful Advocacy Agenda, which will be main thrust of all efforts of NCD Alliance. It would be a guiding principle for NCD organizations while pushing for health system reforms and government policies. The workshop commenced with an introduction from Katie Dain, CEO of NCD Alliance, followed by the description of OVOV consultation and results by Cristina Parsons Perez, Josianne Galea, both from NCD Alliance, and Abish Romero (Mexico), one of the global advisors for OVOV.



(from left to right) The NCD Alliance Team: Cristina Parsons Perez (Capacity Development Director), Josianne Galea (Capacity Development Officer), Katie Dain (Chief Executive Officer)

The sessions during the workshop were divided in to these themes: (1) Treatment, Care and Support, (2) Human Rights and Social Justice, (3) Prevention. The workshop also discussed what will be the further efforts NCD Alliance must go in order for this start can be channelled to where it is really needed most. Moreover, five individuals gave their testimonies on how their own advocacies started.







the Participants, while at work

Work sessions' purpose is to come up with strong introduction and background for each advocacy agenda theme. Treatment, care and support session centered on why PLWNCDs need to demand action, examples and success factors for each organization or country's efforts on this topic and the role of PLWNCDs play to improve their access to treatment, care and support. The central idea each participant tells is how important health is. It is the right of every individual for a good and accessible health care. It was also discussed that government need to invest on a good health system in order to improve the socioeconomic burden NCD has in the society.



Dr. Mahem and Mrs. Dhanya Wijesuriya (*left*) and Phyllis Fehr (*right*) talks about how they started their advocacy on Diabetes in India, and Dementia and Alzheimer's disease in Canada, respectively.

Human rights and social justice session concentrated on the need to include this on advocacy agenda, shared experienced stigma and discrimination, success stories and strategies tackling stigma and discrimination, and ways

PLWNCDs need to take action, obstacles and resources to eliminate stigma and action. It focused on eradicating the stigma and discrimination in family, school, workplace, community and society through awareness and education. The core of this session is to give voice to those who cannot and do not have the means speak: the children, the elderly, the poor, the vulnerable.

The day ended on a lighter note through an evening reception at Restaurant Vieux Bois, which were a few walks away from the workshop venue.



Katie Dain, CEO of NCD Alliance, welcomes everyone for the evening reception before enjoying the 3-course meal

The second day was a continuation of the work sessions and the discussion on the statements included in the Advocacy Agenda. It started with a brief talk from Louise Agersnap, from World Health Organization (WHO) office for Global Coordinating Mechanism, about the WHO campaign “NCD & Me”, wherein any person can write their stories or experience on NCD, whether they are patients, care partners, advocates, or medical practitioners.

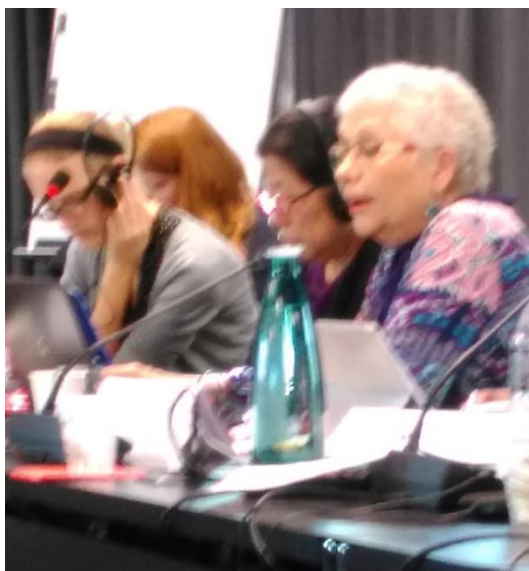




Louise Agersnap (*center*), from WHO talks about the global campaign in relation to NCDs (#beatNCD and NCD & Me)

It became an emotional discussion when participants discussed Community Engagement, as one participant made aware of the group that we cannot speak for others because we do not know what they were experiencing, and in order for this to be truly “Our Voice”, we have to go those villages and rural areas where people need the health care system the most. A memorable quote I remembered from this is: “We are not an interesting case, or a test subject. We wanted to be partners, not just something to be discussed or observed.”

Prevention’s focal point is to eradicate the preventable NCDs through awareness for the public, government policy on health and vaccination, and lifestyle changes with regards to unhealthy foods, tobacco and alcohol. I gave them food for thought on including monitoring and continued follow up for patients, in order to address the complications and co-morbidities especially for unpreventable NCDs such as autoimmune diseases.



Leoni Margarita Simm (Brazil, left) and Linda Askeland (Norway, right) share their stories as patient-advocate and care partner-advocate, respectively.

## Next Step

What is next for NCD Alliance? Draft of the Advocacy Agenda will be sent to the participants for added inputs and views. NCD Alliance will launch the Advocacy Agenda at 2<sup>nd</sup> Global NCD Alliance Forum on 9-11 December at Sharjah, United Arab Emirates. It will be attended by WHO representative, different stakeholders and patients.

Another effort of NCD Alliance is ensuring that there will be NCD representation on 2018 UN High Level Meeting, where heads of states will be attending. NCD Alliance will also be devising an OVOV training programme to continue this initiative and guarantee that more views and voices will be heard. It may also continue to mobilise more OVOV groups. NCD Alliance will also explore a WHO GCM community of practice for the meaningful involvement of PLWNCDs, which may develop principles for engagement of communities. NCD Alliance would also like to know the national and regional advocacy programs of their partner organizations which will strengthen the role of PLWNCDs. The organization will be developing communications programmes to reframe NCD narrative to help progress agenda, and to break down stigma and discrimination. Lastly, NCD will be revisiting and updating the Advocacy Agenda every 5 years to ensure that it will be up to par with the current situation in PLWNCDs.





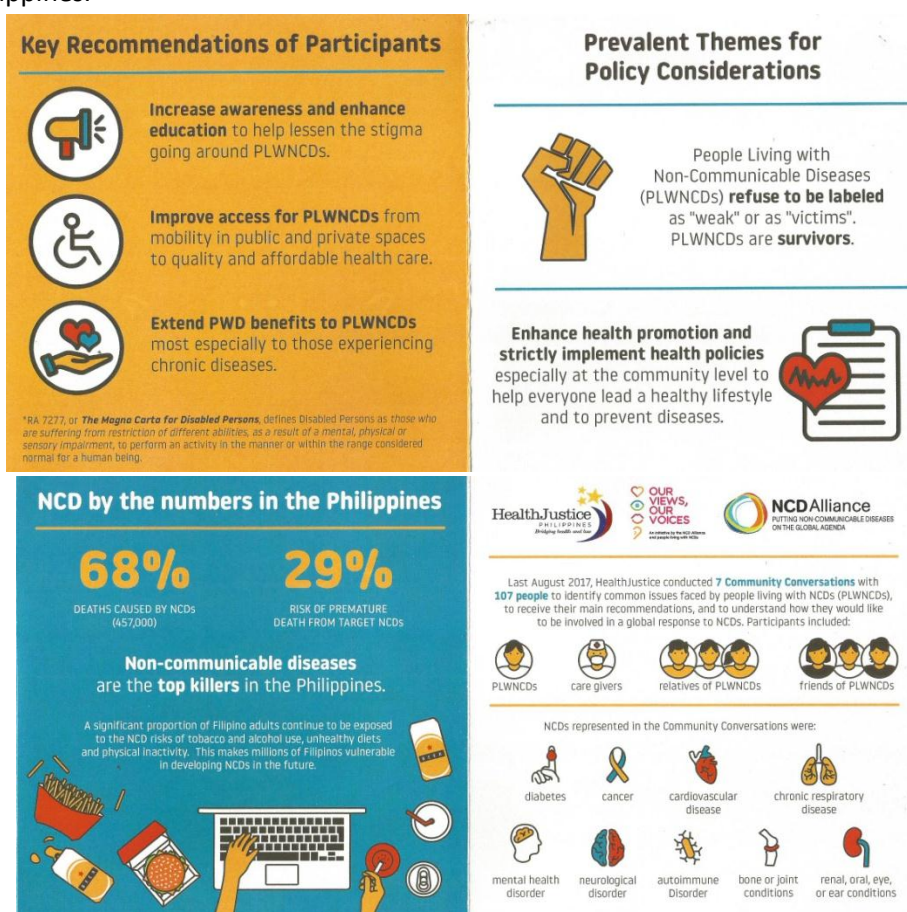
## Dissemination Meeting – B Hotel, Quezon City; 21 November

Last 21 November 2017, HealthJustice Philippines hosted a dissemination meeting regarding the results of the community conversations conducted. The event commenced with a welcome remarks from Dr. Jaime Galvez-Tan, Board of Trustee of HealthJustice Philippines. He stressed the fact that NCD is growing in numbers here in the Philippines, thus, the government and the people have to take an active role in beating these conditions.



Dr. Jaime Galvez-Tan, as he delivers his welcoming remarks

Then Ms. Pauline Marie Villar and Ms. Arianne Balaoing imparted the results from the 7 community conversations conducted in the Philippines.



After which, Robelle Tananganan presented the Advocacy Agenda from the Geneva Workshop, followed by an open forum. The open forum revolved around the inclusion of NCD as persons with disabilities and coordination with government, neighbourhood and families in NCD prevention programs and health promotion policies, which coincides with the results from previous community conversations. Ms. Kim Librero from DOH-HPDPB gave insights on what the

Department of Health has been doing so far in relation to NCD. This half day event concluded with the closing remarks from Mr. Ralph Emerson Degollacion, Project Manager of HealthJustice Philippines, which centered on what we can still do to stop the emergence of NCD, its effect to people and families' lives.



(From left to right) Robelle Tanangunan, Kim Librero and Ralph Degollacion, as they give their insights on NCD



HealthJustice Philippines, with representatives from patient groups who participated in Philippine Community Conversations

### **My Journey to Our Views, Our Voices workshop**

HealthJustice Philippines is NCD Alliance's partner here in the Philippines for OVOV community conversations. Our organization was linked to them by Psoriasis Philippines, with whom we partnered with different activities and events. Through Lupus Inspired Advocacy, I coordinated with 20 lupus patients who consented to be part of one conversation.

When HealthJustice Philippines informed me that they would like to nominate me to represent Philippines to this workshop, I immediately said yes, as this is an amazing opportunity to help lupus and Filipino patients' voices is heard. I had a few apprehensions, as this is the first time I will be travelling such a long way without any colleagues with me. And to top it off, the weather in Geneva way what I was used to. It was really a touch and go with the Schengen Visa application due to the time my nomination was approved and the days I needed to complete the documents necessary for the application. I was able to submit my application on 16 October; visa processing takes 5-10 days because Swiss embassy has been using a third-party agency; and I have to leave 28 October. My visa was released on 24 October.





My flight (Qatar Airways) is a 19-hour flight, including a 5-hour layover at Hamad International Airport in Doha, Qatar. I also have to start shifting my body clock to the time in Switzerland as it has a 7-hour delay difference from Philippine time. By Saturday, I took my medicines at Geneva time, in order to slowly shift my body clock. Moreover, I have to take public transport by myself from the Geneva airport to the hotel, and around Geneva. Good thing that I met Mr. Carlos Garcia, another Filipino representative from Vital Strategies. This is also the first time that I will be attending an international event for patients, as in the past, all my travels are attendance to a medical conference about lupus and arthritis. Thus this experience is truly refreshing and overwhelming, The workshop will not be complete without a few anecdotes.

There was a time when Mr. Carlos and I headed the wrong way in the tram, trying to get to Basilique Notre-Dame de Geneva. Another was during Day 1 of workshop when all of the participants were not ready to battle with the 0°C temperature and windy weather, but tried to walk from the bus station to the workshop venue, only to find out we are in the wrong building.

I got to meet a lot of amazing individuals who have been advocates of their diseases in their own countries for many years. I am humbled by this experience because of all the efforts they do in their own countries despite limited resources, information and awareness. Never in my wildest dreams did I think I will be able to go to Geneva, and explore the city, visiting Basilique Notre-Dame de Geneve, United Nations Office in Geneva, World Health Organization, and all those other places I just read on books, or saw on the Internet.



I would like to take this opportunity to thank HealthJustice Philippines for nominating me to represent Philippines in this workshop. I would also like to thank Mr. Ralph Emerson Degollacion, Ms. Pauline Marie Villar and Arianne Balaoing for all the support and study materials from Philippine conversations. I would like to thank Ms. Josianne Galea and Ben Romoff of NCD Alliance for all the organization and arrangement for my visa and travel. I would also like to thank Mr. Josef de Guzman for linking Rheumatology Educational Trust Foundation, through the Lupus Inspired Advocacy project, with HealthJustice Philippines for the Philippine conversations, which paved way for my nomination. Last, but definitely not the least, Dr. Sandra Navarra for all the support for my attendance to the workshop.