

## Volunteer Youth Leaders for Health - Philippines: Providing a Mechanism for Youth Empowerment towards Advocacy for Birth Defects Prevention and Care

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### ABSTRACT

The Volunteer Youth Leaders for Health - Philippines (VYLH-Philippines) is a national youth network established in 2009 as a model of how to organize young women and men into a national force that promotes self-learning, independence, personal growth and sustained positive public health change from the grassroots level and up. Formed under the aegis of the University of the Philippines Manila and the Department of Health, the VYLH-Philippines has focused its activities in the past eight years on helping reduce mortality and disability from congenital disorders through awareness programs and support for policy development. This paper describes in detail the organization and extraordinary accomplishments of the VYLH-Philippines to date.

*Key Words: volunteer youth leaders, volunteers, rare diseases, birth defects, newborn screening, public health*

### Introduction

It is only recently that governments, United Nation entities, regional and multilateral organizations, civil society organizations and researchers have begun to recognize that the participation and leadership of youth is essential to achieve sustainable human development. A major highlight in 2015 was the International Youth Day held August 12

with “Youth Civic Engagement” as its theme.<sup>1</sup> It coincided with the release of the final document of the Sustainable Development Goals (SDGs) by the UN General Assembly, agreed by consensus among governments earlier in the month.<sup>2</sup> Although the concurrence of these two events may not have been planned, it highlighted the significance of the year 2015 with the release of the SDGs as a historic opportunity for young people and for the governments that serve them, with the post-2015 outcome document recognizing that “children and young women and men are critical agents of change.”

In the Philippines, volunteerism has had a long, rich, diverse, cultural tradition. Under its many cultural names, guises, and dimensions, volunteerism remains embedded in the tradition of sharing and of helping. Notions of Filipino volunteerism employ various indigenous meanings such as *bayanihan*, *damayan*, *kawanggawa*, *pahinungod*, and *bahaginan*,<sup>3</sup> which can translate into various types of volunteering such as academe-based volunteering, corporate volunteering, government-supported volunteering, nongovernmental organization volunteering and foreign-supported volunteering. Every volunteer group has a mission and a targeted group to serve, such as street children, the elderly, and patients, etc. All of these volunteer activities bring significant benefits to individuals and the communities in which they live.

The youth is a viable and dynamic sector of society that can be tapped for volunteer work. In the Philippines, the role of the youth in nation building has been enshrined in its Constitution. It has also been the policy of the State to promote and protect the well-being of the sector, as well as

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encourage their involvement in public and civic affairs. Republic Act 8044 or the Youth in Nation Building Act provides the definition of youth in the Philippines as individuals ages 15 to 30 years old. Furthermore, the law declares that “Youth” is a “critical period in a person’s growth and development from the onset of adolescence towards the peak of mature, self-reliant and responsible adulthood.”<sup>4</sup> As the future leaders of society, the youth has also been regarded as the most valuable resource of the nation.<sup>5</sup> Table 1 summarizes the key national policies and proposed legislations on volunteerism and youth participation.

In recent years, there has been a shift from seeing the youth as problems to viewing the sector as resources for participatory development.<sup>6</sup> Youth health promotion has also gained recognition as a viable approach on preventing youth health problems, but also enhancing positive development.<sup>6</sup> It is known that many of the habits and health behaviors observed in adulthood begin during this stage. The World Health Organization has also pointed that promoting healthy practices during the adolescence and reproductive age, and planning for strategic actions to ensure that the young people are protected from health risks is critical to the future of a country’s health and social infrastructure.<sup>7</sup> Recognizing this, some countries have started to train youth as advocates for public health and

agents in raising awareness among their peers about critical health issues that confront their health and the health of future generations.<sup>8</sup>

In 2009, the Volunteer Youth Leaders for Health of the Philippines (VYLH-Philippines) was organized with three initial projects in mind: raising national awareness about the importance of folic acid supplementation in the prevention of neural tube defects; newborn screening for the prevention of mental retardation and death; and advocacy for the passage of a Rare Disease Act – a legislation that provides a comprehensive package of affordable and accessible health care for patients with rare diseases. With seed funding from the March of Dimes Foundation, the Institute of Human Genetics - National Institutes of Health, and the Department of Health, the VYLH-Philippines was established as a model in organizing young women and men into a national force that promotes self-learning, independence, personal growth and sustained positive public health change from the grassroots level and up.

The principles binding the members of VYLH-Philippines are leadership, commitment, advocacy, and volunteerism. VYLH believes that collectively the youth sector can lead, in collaboration with other sectors in nation building by working towards a healthy society; that in order to play a critical role in nation building, unrelenting commitment to humanitarian endeavor that benefits the

**Table 1.** Key national and proposed policies on volunteerism and youth participation in the Philippines

| Year | Policy  | Salient Points  |
|------|---|---|
| 1987 | 1987 Constitution of the Republic of the Philippines*                   | The State recognizes the vital role of the youth in nation-building and shall promote and protect their physical, moral, spiritual, intellectual, and social well-being. It shall inculcate in the youth patriotism and nationalism, and encourage their involvement in public and civic affairs. (Article II. Section 13)  |
| 1991 | Republic Act 7160 Local Government Code*                                | The law created the <i>Katipunan ng Kabataan</i> (youth federation) and the <i>Sangguniang Kabataan</i> (SK, youth council) at the barangay (village) level, as well as the SK Federation at municipal/city, provincial, and national levels.   |
| 1995 | Republic Act 8044 Youth in Nation Building Act*                         | The law defines the youth as persons from 15 to 30 years old. It also created the National Youth Commission and constituted the National Youth Parliament   |
| 2001 | Republic Act 9163 National Service Training Program (NSTP) Act of 2001* | The youth as the most valuable resource of the nation shall be motivated, trained, organized and mobilized in military training, literacy, civic welfare and other similar endeavors in the service of the nation.<br>The act establishes the Civil Welfare Training Service (CWTS), and Literacy Training Service (LTS) as additional components of the NSTP.  |
| 2007 | Republic Act 9418 Volunteer Act of 2007*                                | The promotion of the participation of the various sectors of the Filipino society in public and civic affairs and adopt, and strengthening of the practice of volunteerism as a strategy to attain national development and international understanding shall be included in the policies of the State.<br>The law mandates the integration of volunteerism in the Basic and Higher Education Curriculum to raise the consciousness of the youth and develop the culture of volunteerism among the citizenry.             |
| 2016 | Republic Act 10742 Sangguniang Kabataan Reform Act of 2015*             | The law expanded the SK membership from 15-21 years old to 15-30 years old. The law also mandates the creation of Youth Development Councils and organization of Youth Development Offices in various level of government.  |
| 2016 | House Bill 146**<br><br>Senate Bill 1074***                             | The proposed amendment on RA 9418 focuses on institutionalizing volunteerism as a strategy for national development through the provision of appropriations for the Philippine National Volunteers Awards Program<br>A bill providing the legal and institutional framework for a strategic volunteerism-based multisectoral public-private partnership through the “Filipino Volunteerism in Nation Building Program (VNB)” to be coordinated by the Philippine National Volunteer Service Coordinating Agency (PNVSACA) |
| 2017 | Senate Bill 1418****  | A bill on the protection of volunteers from liability in the performance of volunteer services as long as the volunteer acted within the scope of responsibilities, the volunteer was properly authorized, and the harm was not caused willfully or the indifference to the rights and safety of another.   |

\* Compiled from the Official Gazette (<http://www.gov.ph>), the Official websites of the Philippine Senate (<http://www.senate.gov.ph>) and House of Representatives (<http://www.congress.gov.ph/>) (accessed September 26, 2017).

\*\* [http://www.congress.gov.ph/legisdocs/basic\\_17/HB00146.pdf](http://www.congress.gov.ph/legisdocs/basic_17/HB00146.pdf) (accessed September 26, 2017).

\*\*\* <http://www.senate.gov.ph/lisdata/2466421257!.pdf> (accessed September 26, 2017).

\*\*\*\* <http://www.senate.gov.ph/lisdata/2580722186!.pdf> (accessed September 26, 2017).

general public is of utmost importance; that the network, in collaboration with government and non-government health agencies at all levels, shall advocate for the health needs of the youth sector and general public towards a healthy future; and that the spirit of volunteerism should be inculcated in the minds of the youth, making them more responsible and concerned citizens.

The VYLH-Philippines focuses on congenital disorders (birth defects) in recognition of the fact that children with congenital disorders remain left behind in policies, programs, research, and funding. This is a massive public health gap as the global toll of congenital disorders is severe. An estimated 7.9 million children are born each year with a genetic or partially genetic (multifactorial) congenital disorder, and several hundred thousand more are born with congenital disorders due to post-conception in utero insults such as infections and exposures to teratogens such as alcohol.<sup>9</sup> At least 3.3 million children under five years of age die from birth defects each year and an estimated 3.2 million of those who survive may be disabled for life. The March of Dimes reported the estimated prevalence of congenital disorders was 52.9 per 1,000 live births in 2006.<sup>9</sup> In the Philippines, congenital malformations (called congenital anomalies prior to the year 2000) are among the top ten causes of infant mortality for the past 50 years (1960-2010).<sup>10</sup> In 2010, 0.9 deaths per 1000 live births were attributed to congenital malformations of the heart and another 0.5 deaths per 1000 live births were due to other congenital malformations. However, the burden of birth defects at the national level is not well established in the Philippines due to the absence of a national registry.<sup>11</sup> The current surveillance project spearheaded by the Institute of Human Genetics, NIH-UP Manila and the Department of Health (Philippines) is still limited.

#### **Recruitment and Organizational Structure**

The VYLH-Philippines is unique in many ways, beginning with how the volunteer youth leaders (VYLs) were first recruited. In 2009, letters were written by the author (C Padilla) to the Presidents of top universities and colleges across the Philippines introducing them to the goals of the VYLH-Philippines and requesting that they identify a top student leader interested in joining the team. Selection criteria for the VYLs were based on the following: that they be a) existing members of school-based and community-based youth organizations, b) actively involved in socio-civic activities, c) influential among the youth sector in the school and community, d) open to partnership with the local government health unit in implementing health activities, and e) 18 years or older.

It was not essential that the students identified be enrolled in a health sciences course such as public health, pharmacy, nursing or medicine. In fact, primacy was placed on identifying VYLs representing a broad range of

disciplines, including health, engineering, biology, environmental science, education, business administration, information technology, and communication arts. It was felt that the contributions of an interdisciplinary group would be more creative and dynamic and consonant with the holistic framework of the SDGs. Emphasis was also placed on identifying youth leaders from a number of different geographic regions across the Philippines to ensure that VYLH-Philippines programs, including curricula and messaging, were inclusive and accessible to the many different ethnic groups that contribute to the cultural richness of the Philippines. Also, the broad geographic makeup of the network would allow for the tailoring of programs as needed to the unique health needs and cultural sensitivities of specific target populations.

Figure 1 presents its current organizational structure. The structure of VYLH-Philippines is a network grounded on individual youth leaders and the affiliated youth organizations from universities and communities throughout the Philippines. Leadership in the network is grouped into four levels: local, regional, cluster, and national. At the grassroots, each member organization shall provide two duly designated representatives who undergo the network's training program and serve as the liaison officer between the network and the member organizations. The organizations, their members, and their official representatives are grouped into regions wherein two Regional Coordinators are elected. The 17 political regions are further grouped according to Clusters. At present, there are four clusters in the network: North Luzon, NCR-South Luzon, Visayas, and Mindanao. Two elected Cluster Coordinators head each cluster. The organizational/local representatives, regional and cluster coordinators are tasked to orient and coordinate their members regarding the plans and current status of their advocacy and networking activities. The cluster coordinators also report and act as members of the national leadership that is composed of the executive committee, the Secretariat, and the Board of Advisers.

The Executive Committee is headed by the elected National President, the four lead coordinators of every cluster acting as the four Vice-Presidents of the network, the Secretary, the Treasurer, Auditor, Public Information and Relations Officer and National Membership Officer. The Executive Committee is elected every two years during the National Congress. The Board of Advisers is composed of the National Program Adviser; the Director of IHG-NIH, UP Manila; the Director of the Newborn Screening Reference Center (NSRC); a representative from the DOH, and Unit Heads of Newborn Screening Centers (NSCs). At present, each cluster is supervised by a Unit Head of an NSC. The Network Secretariat supports the Cluster Adviser and volunteer coordinators in the supervision of the network at the Cluster level and below. The network has a national secretariat and one secretariat for each cluster.

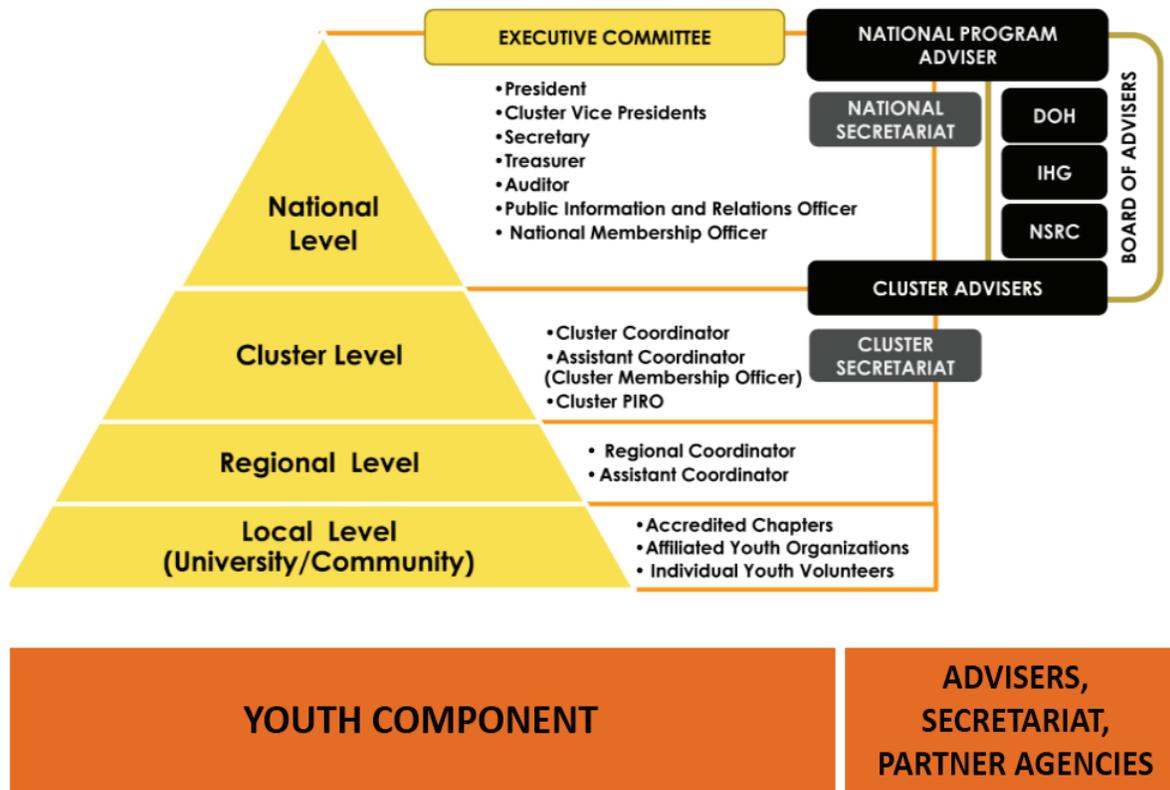


Figure 1. Organizational Structure of VYLH-Philippines.

**Accomplishments to Date**

During the formation of the network particularly the First National VYLH Camp, the pioneer student facilitators from the University of the Philippines-Los Baños (UPLB) Genetics Society were assisted by national health leaders, youth advocates, advocates of volunteerism, geneticists, and educators in training the new volunteers. Subsequent activities such as the series of provincial, regional, island-wide, cluster camps, and national congresses were then organized, facilitated, and managed by different batches of volunteer youth leaders. It was during these activities where the pioneer volunteer youth leaders were able to exercise and hone their leadership and facilitation skills, while mentoring their peers and younger volunteers. It is a tradition in the network to pass on leadership responsibilities from one batch to the next in order to sustain and strengthen the organization.

Since 2009, the major leadership and volunteer formation activities of the network have been conducted through a two to three-day youth camp organized by youth volunteers and held through the support of partner agencies. The camp program includes discussions on the networks, its objectives, principles and activities; capacity building on public speaking, action planning, policy and lobbying; and networking, organizing, and mobilizing the public, especially the youth sector. Invited experts and youth volunteers also discuss the importance of volunteerism and

the advocacies of the network. Group dynamics and other interactive activities such as the team building activity and group cultural presentation are also conducted in between activities in order to continuously capture the attention of the participants and build rapport among the volunteers. To mark the official involvement of youth participants as volunteer youth leaders, a solemn and symbolic commitment setting activity has been continuously practiced by the network through the years. One of the important outputs of the youth leaders during the training is the action plan. The action plan serves as the basis of the participants in implementing activities in their respective institutions and communities. In June 2016, the network launched a community-based youth training program known as “K4Health” (*Kabataan for Health or Kabataang Kabalikat ng Komunidad para sa Kalusugan*) [Youth for Health or Young Partners of the Community for Health] which aims to organize and train youth leaders from various cities and municipalities in the country. In these programs, the youth are also introduced to community health and development, and the existing health situation in the community. As part of the partnership with the local government and health officials, the emerging health concern of the community is also presented in addition to the advocacies of the network. The participants are also further equipped in health promotion through problem tree analysis and advocacy demonstration. Officers and youth coordinators at the local

or cluster level are also elected during youth camps in order to streamline and institutionalize the communication and leadership channels of the network.

In a span of eight years (2009-2017), VYLH-Philippines has trained 773 volunteer youth leaders representing 195 youth organizations from 123 higher education institutions and 87 communities nationwide. In terms of coverage, the trained youth leaders of the network have represented all of the regions of the country as depicted in Figure 2. It

demonstrates the national nature of the VYLH-Philippines. Every major region across the vast archipelago is represented in the network.

The accomplishments cover a wide range: development of communication strategies, training in policy development and advocacy, partnerships with government agencies, academe and NGOs, leadership congresses, participation in local and international conferences, and hosting of leadership camps.

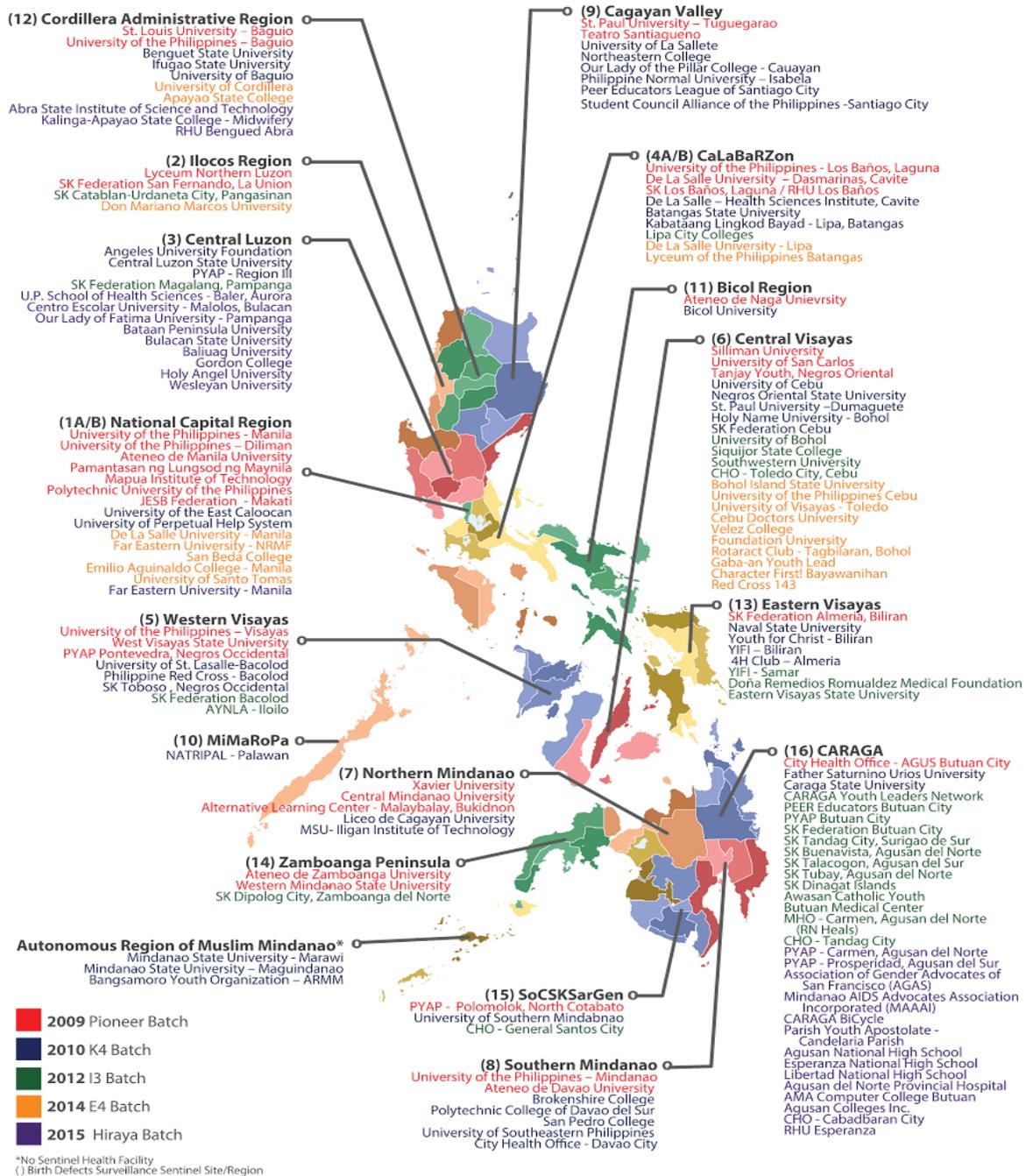


Figure 2. Distribution Map of Represented Higher Education Institutions and Community Groups in the VYLH-Philippines Network (2009-2015).

### *Development of Communication Strategies*

Members of VYLH-Philippines (VYLs) have continuously developed print and accessible online resource materials; designed communication tools and strategies; and organized community and school lectures, symposia, and exhibits. VYLs together with technical partners from the Institute of Human Genetics-NIH, UP Manila developed the Folic Acid Campaign Brochure and Awareness Assessment test. VYLs from Ateneo de Zamboanga University have developed a springboard module entitled “Baby Making 101” for the presentation and discussion of the advocacy on birth defects among students and other target participants. The interactive learning activity wherein participants are asked about the preferred physical attributes of a first-born highlights birth defects care and prevention. VYLs from Dumaguete City initiated “Jam for Life” – a community activity wherein the three flagship advocacies of the network were presented in a night of music and inspiration.

VYLs have created and maintained a website, a blog, and other social media platforms that allowed the public to access information and updates about the network and its advocacies and download campaign-related materials. The following are the links of their social media accounts:

- Facebook page: <https://www.facebook.com/groups/380866198617627/>
- VYLH Community Facebook page: <https://www.facebook.com/vylhphilippines>
- VYLH website: <https://sites.google.com/site/vylhphilippines/>
- VYLH blog: <http://vylhphilippines.blogspot.com/>

The network has also pioneered youth-led on ground and social media activities such as the “NBS (Newborn Screening) Hour” and “WorldBDday Thunderclap Hour”, “Schools for Rare” and the “I am Rare” worry-free and fun day outreach activity for rare diseases patients and their guardians.

### *Training in Policy Development and Advocacy*

Members of the network have also successfully lobbied for the issuance of policies related to the advocacies of the network at the local and national level. VYLH volunteers were able to lobby the issuance of various local ordinances and resolutions.

- In 2010, a local resolution adopting the provisions of the proposed Rare Disease Act of the Philippines in Santiago City was issued through the efforts of a pioneer volunteer in collaboration with local legislators.
- In 2011, a *Sanggunian Kabataan* (Local Youth Council) Resolution supporting the Volunteer Youth Leaders for Health and its advocacy implementation in Masao, Butuan City was issued.
- In 2012, a resolution was issued calling the DILG and DOH to strengthen the maternal-, child-, and youth-

friendly health services in all health centers in the Philippines, and mainstreaming the importance of folic acid supplementation and newborn screening to prevent neural tube defects and mental retardation during the 9th National Youth Parliament organized by the National Youth Commission.

VYLs actively participated and led the youth in lobbying the passage of the Rare Disease Act of 2016 through a signature campaign during their community and school activities. Some of the VYLs attended public hearings at the Senate and Congress. They also attended roundtable discussions with stakeholders and concerned agencies.

The network actively participates in local and international observances related to the youth and the advocacies of the network such as National Rare Disease Week, World Rare Disease Day, National Pregnant Women’s Day, and National Newborn Screening Week. In separate locations across the country, VYLs have participated in the National Pregnant Women’s Day (*Pambansang Araw ng mga Buntis*) activities.

VYLH-Philippines was the lead youth organization during the first observance of World Birth Defects Day in the Philippines (WorldBDday 2016). The network was able to mobilize 21 student organizations, councils, and alliances for the event. The network has established partnerships with professional societies, national government agencies, civil society groups, and youth organizations for the observance and promotion of World Prematurity Day and World Birth Defects Day in the Philippines.

Various materials were also prepared and made available online for World Prematurity Day, the global campaign for preterm birth awareness and prevention.

### *Partnerships with government agencies, academia, and NGOs*

The network has also established partnerships with local agencies and professional organizations such as, the DOH Regional Offices (Centers for Health Development), Newborn Screening Reference Center, Newborn Screening Centers (NIH, Central Luzon, Visayas, Mindanao), Philippine Society for Orphan Disorders, Philippine Obstetrical and Gynecological Society, and Philippine Society for Newborn Medicine.

### *Leadership Congresses*

Aside from its year-round health promotion and advocacy projects, the network has also conducted national leadership congresses, orientations and youth camps for the recruitment and training of volunteer youth leaders. The National Leadership Congress (held in 2011, 2012, and 2013) aims to strengthen the network; re-commission the volunteer youth leaders; update members about program developments and plans; discuss relevant and timely health issues; assess the progress of the network; and identify best practices that can be standardized and adapted by the

network. Through the National Leadership Congress, the network was able to elect its officers and develop its Constitution and By-laws, Membership Guidelines, and Program Implementation Guidelines.

#### ***Participation in Local and International Conferences***

VYLH-Philippines has also participated and presented the network's programs and achievements in various local and international conferences.

- Three international conferences: International Conference on Birth Defects and Disabilities in the Developing World (2013), International Young Food and Nutrition Leadership Training and Workshop (2014) and the Asian Congress of Nutrition (2015).
- In 2012, VYLH-Philippines joined the National Conference on the Engagement of the Academe on Volunteerism (NCEAV) organized by VSO Bahaginan at Miriam College. A talk entitled "Volunteers in Health: The VYLH-Philippines and IHG-UP Manila Experience" was presented by the network's co-founding adviser, Dr. Merlyn Mendioro. The network also had an exhibit/booth during the event. The NCEAV was participated by various universities, colleges, and volunteer organizations. In 2015 alone, five local conferences were attended by the network: Cordillera Youth Congress (January), Global Youth Summit-Manila (March), 13th National Newborn Screening Convention (October), 1st Colleges and Universities Public Service Conference (November), and 1st CARAGA Newborn Screening Convention (November).

#### **Youth Leadership Awards**

In 2014, The VYLH was a recipient of the first ever Voice of the Youth (VOTY) Awards. It is given by the VOTY Network during the Global Youth Service Day (GYSD), an annual international gathering of young volunteers spearheaded by Youth Service America (YSA). The event is conducted every April and is celebrated in more than 135 countries. It is dedicated to children and the youth and is claimed to be the largest service event in the world, since its establishment in 1988. For four years now, the Voice of the Youth Network (VOTY) is the chosen campaign partner in the Philippines. In 2014, VYLH-Philippines Programs were recognized by the Voice of the Youth Network as one of the Outstanding Health Awareness Projects in celebration of Global Youth Service Day.<sup>12</sup> In April 2016, the Office of Population and Reproductive Health, Service Delivery Improvement Division, U.S. Agency for International Development contacted VYLH-Philippines to inform the group that it has been selected as one of the top 5 programs of the USAID Leadership, Management & Governance (LMG) Project and the International Youth Alliance for Family Planning (IYAFP).<sup>13</sup> USAID LMG continually identifies multi-sectoral youth leadership programs from

around the world that have demonstrated positive outcomes for youth, organizations, and communities, and contribute to service delivery improvements. As stated in their letter: "We believe your program is an excellent model to learn from. We would like to share key strategies with others who are implementing programs that support the next generation of leaders".

#### **Future Plans**

VYLH Philippines has developed a three-year plan with a primary goal of strengthening and expanding the network locally and internationally. Included in this plan is reviewing and redefining the network's programs and advocacies, considering the need to adapt to the progress achieved in the past, current needs and future advocacies, and direction of the network. Furthermore, the network plans to conduct a youth awareness assessment of impact in communities served, as well as develop and produce a manual of operations which is important in standardizing the practices and program implementation of the network. Moreover, the network will continue its expansion phase through the conduct of youth camps that will allow the recruitment of new volunteers particularly in areas with a minimal number of volunteers. Finally, the network also envisions to share the VYLH model with other regions of the world through participation in international youth meetings and the possible hosting of an international summit on role of the youth in health promotion and advocacy.

#### **Conclusion**

Young people have unbounded energy, passion, and creativity and the spirit of volunteerism is alive and thriving in the Filipino youth. The VYLH-Philippines has shown that young people can be effective partners in nation building, tackling health issues, and promoting numerous health-related advocacies. As shown in this paper, the youth can support and spearhead programs related to birth defects prevention and care with the use of traditional and emerging tools in health promotion the youth can create novel paths and form networks to accomplish valuable goals. The power of the youth should not be underestimated as they can achieve with proper guidance and appropriate support. They are, indeed, our country's hope.

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**Statement of Authorship**

All authors have approved the final version submitted.

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**Author Disclosure**

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