



advocacy toolkit



Introduction

Purpose of this advocacy toolkit

The purpose of this toolkit is to help individuals and organizations advocate to improve the health and well-being of congenital and rheumatic heart disease patients. It offers information and practical tools on how to carry out advocacy efforts in your community.

This toolkit describes how to identify advocacy goals and how to communicate them to different audiences. It includes examples of key messages, letters to policy makers and other materials that can help anyone make the case for needed action. We, Global ARCH and Children's HeartLink, developed this toolkit and encourage users to adapt and update these resources to reflect that situation in their country and region.

Who is the toolkit for?

The toolkit is for patient and family organizations, nongovernmental organizations (NGOs), civil society groups, professional organizations/societies and individuals.

The toolkit has five sections:

SECTION 1: Why

Define the problem

SECTION 2: What

Define advocacy goals

SECTION 3: Who

Determine target audiences

SECTION 4: How

Making and executing an advocacy plan and developing key messages

SECTION 5: Measuring Success

Change measuring success to measuring impact

SECTION 1:

Why – Define the Problem



What is advocacy?

Advocacy is the process of taking collective action that results in needed policy change. Health advocacy focuses on improving the health and well-being of people with health conditions. Health advocacy typically calls for policy change, such as changes in funding or services. To be successful, advocacy must be planned, targeted and have specific goals. Your goals and strategies must be appropriate to your community and reflect the needs of the people in your area. Collaboration, flexibility and patience are also essential. Achieving your advocacy goals often takes a long time and requires many different strategies. Remember to celebrate every step forward, no matter how small.

Why advocate for childhood-onset heart disease?

There are two major ways children develop heart disease. Some children are born with a defect of the heart, called congenital heart disease (CHD). It is the most common birth defect and affects about one out of 100 children. Many children with CHD need surgery or other treatment to survive. Even after surgery, CHD is a lifelong disease that needs ongoing care.

Other children develop rheumatic heart disease (RHD). This is caused by an untreated strep infection. The infection spreads to the heart and damages the heart valves. RHD typically starts between age 6-12 but it can start earlier or later. People often get diagnosed as adolescents or young adults when serious symptoms typically begin. RHD is also a lifelong disease that requires ongoing care. In richer countries, where people have access to antibiotics and diagnosis, RHD has mostly been eliminated. But it is still common in many poorer countries and communities.

CHD and RHD can affect emotional and social well-being. Many families struggle with the costs of care and the challenges of taking care of a sick child. People living with CHD or RHD can face social stigma and discrimination at work and school. Many have ongoing health and social challenges, and need support along the way, including social benefits. Advocacy for people with CHD and RHD can focus on improving social and economic conditions as well as improving health.

Even though CHD and RHD are major causes of death and disability, global awareness of both diseases continues to be limited. Policy makers in many countries continue to neglect addressing the unmet health and social needs of people with heart disease that starts in childhood.

RHD is the most common children's heart problem in many low-income countries. Worldwide there are an estimated 33 million people living with RHD

SECTION 1: Continued

The right to health and well-being

The Constitution of the World Health Organization (WHO) states that every person has the right to health and well-being. Almost every country in the world has committed to achieving this right for their citizens. By taking action together, we can help people living with CHD and RHD achieve this basic right.

Global ARCH developed the [Declaration of the Rights](#) of Individuals Affected by Childhood-Onset Heart Disease. Below is a summary; refer to the Advocacy Resources section in the Appendix for the full declaration. This declaration can serve CHD and RHD communities as a tool to develop and execute advocacy efforts and help them advocate for their rights. It also lists actions that governments should take to meet these rights.

HERE IS A SUMMARY:

Every person with childhood-onset heart disease has the right to health

They have the right to heart care that is:

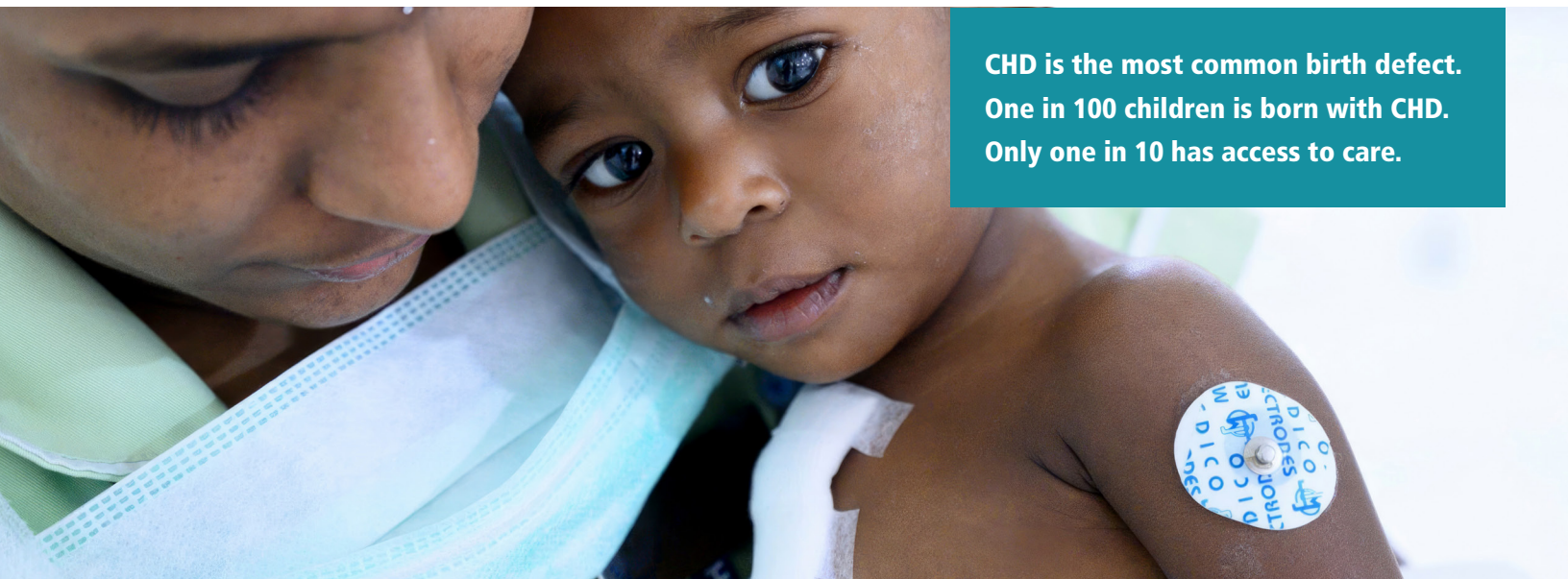
- Affordable
- High-quality
- Lifelong
- Accessible
- Safe
- Patient-centered

They have the right to well-being including:

- Protection from stigma
- Education
- Medical privacy
- Social inclusion
- Employment
- Social benefits

To achieve the rights of CHD and RHD patients, every government should:

- Fund disease detection, heart surgery and lifelong care
- Ensure every patient can reach care when they need it
- Enforce quality standards for CHD and RHD care
- Collect and report information on CHD and RHD health in their country
- Protect CHD and RHD patients from discrimination
- Provide CHD and RHD patients with needed social services and benefits
- Provide social support and promote CHD and RHD patient and family organizations



CHD is the most common birth defect. One in 100 children is born with CHD. Only one in 10 has access to care.

SECTION 1: Continued

Childhood-Onset heart disease fact sheet

Key messages for advocating for childhood-onset heart disease

- All children should have access to safe and high-quality CHD care, regardless of ethnic origin, economic circumstances, or where the care is delivered. All children and families should have the same access.
- Of the 1.35 million children born each year worldwide with CHD, over 90% live in places that do not have adequate access to diagnostics or care.
- CHD is a complex disease requiring a comprehensive multidisciplinary approach at all levels of the health system.
- Quality of care is vital to pediatric cardiac care.
- Improved quality care for children with congenital heart disease CHD and RHD leads to more efficient and cost-effective care.
- Untreated heart disease in children results in a lifelong and life-threatening disability, causing economic hardship to families and lost productivity to the community. Yet, the cost of treatment can be irrevocably impoverishing.

Key facts about childhood-onset heart disease

- CHD occurs in 1 in 100 births and makes up 1/3 of all birth defects.
- 1.35 million children are born with CHD worldwide and it is a top cause of infant mortality globally.
- 1 in 4 children with CHD need infant surgery to survive; most need surgery during childhood and possibly as adult.
- RHD is caused by untreated infection and can be prevented with antibiotics.
- RHD affects 39 million people worldwide and kills 319,000 people each year. It is the most common heart problem that develops during childhood.
- RHD is rare in rich countries and common in many low-income countries and communities.
- CHD and RHD are chronic diseases and need lifelong care.

Lifelong impacts of childhood-onset heart disease

- High risk of heart rhythm problems, heart failure, valve failure, stroke and heart infections.
- Need for one or more open heart surgery.
- High rates of pregnancy-related health problems and death.
- Need for long-term use of blood thinners and/or antibiotics.
- Need for life-long access to regular heart check ups including echo and EKG.

Global barriers to the right to health in childhood-onset heart disease

- 90% of the world's children have no access to heart care including life-saving surgery.
- Less than 20% of the world's population can access needed heart diagnosis and on-going treatment.
- Patients and families face a high financial burden due to the cost of care. The cost of treatment commonly results in catastrophic health costs.
- The majority of RHD and CHD adults worldwide do not receive needed long-term care.
- Most women with CHD and RHD do not receive needed pregnancy management.
- Significant global and in-country outcomes disparities exist based on income, race and ethnicity.
- Patients often face social stigma and discrimination in employment and education.

SECTION 2:

What – Define Advocacy Goals

Laying the foundation: listening to patients and families

Advocacy is a group effort. The strongest advocacy starts with bringing together a group of people facing common challenges. Around the world, CHD and RHD patients and family members come together to offer each other support and peer education. Each has experienced challenges caused by the disease, whether they are physical, social, emotional or financial. Listening to their stories will give essential information about the problems that are most important to address. Learning from the people affected by the disease will ensure that the advocacy efforts focus on issues that matter most to the whole community.

Patient and family groups can range from informal online discussion groups, hospital-based support groups or independent organizations focused exclusively on the needs of CHD and RHD patients and families. Leaders of or participants in patient and family groups now have an essential resource to inform their advocacy. Humanitarian or clinical organizations also should look for opportunities to bring patient and families together to share their stories.

Research the problem to develop an advocacy goal

1. If the aim is to make a policy change:
 - Understand existing policies and who would be responsible for making changes.
 - Does the government have goals, targets and indicators aligned with the goals of your advocacy?
 - Who is responsible for the monitoring and surveillance of the issue you are advocating for?
 - Why should policy makers care about the problem?
 - What are the main barriers that patients face in accessing care?
2. Find trusted sources to learn more and speak with stakeholders to understand their viewpoint on the issue.
3. What information should be shared and who would be the most helpful to share it with?

Before establishing an advocacy goal, consider

1. Can you demonstrate how it will impact those most affected?
2. Is it feasible / winnable?
3. Is it easy to understand and explain?
4. Will it attract support?
5. Who else is advocating for this?



EXAMPLES OF ADVOCACY GOALS

GOAL: Generate awareness through publication and dissemination of data, research and personal testimonies, or to build awareness within communities and change perceptions about childhood-onset heart disease.

GOAL: Advocate for policy change by reaching out to policy makers and leaders and influencing them to make changes to policies relevant to people with childhood-onset heart disease.

For example:

- Including CHD and RHD in official health planning
- Increase investments in pediatric cardiac care
- Policy Development – New proposals or guiding principles developed

GOAL: Hold governments accountable to international and domestic commitments and encourage them to engage with international bodies to promote improved access for pediatric cardiac care.

For example:

- Maternal and child health commitments to reduce childhood mortality
- Universal health coverage commitments to improve affordability of health care
- Non-communicable disease (NCDs) commitments to plan for non-communicable diseases services
- Surgical systems planning commitments – to assure quality and safe surgical services

GOAL: Engage with professional organizations to encourage and support quality and best practice guidelines for advocacy efforts.

For example:

- Inclusion of CHD and RHD in official global guidance and recommendations on clinical care and financing

SECTION 2: Continued

Build partnerships

Successful advocacy efforts are collaborative. It is much easier to achieve policy change when there are many organizations calling for action. When defining advocacy goals, it is important to identify which organizations are the most important allies. All successful collaborations are built on knowledge and trust. Below are some suggestions of ways to connect with various kinds of organizations.

1. Multi-Organizational coalitions

In some areas, there are multiple organizations focused on CHD and/or RHD. These may include patient organizations, organizations that raise funds for care, or humanitarian organizations that provide healthcare services. These organizations can have little contact with each other and may even be in competition. Successful advocacy efforts rely on creating alliances between organizations that share common goals. Reaching out to group leaders and inviting participation in joint activities are some simple ways to connect.

2. Organizations that focus on broader health categories that include CHD and RHD.

These might include:

- Organizations that address heart disease in general
- Organizations that address birth defects or childhood health
- Organizations that address non-communicable disease (NCDs)

These organizations may already include CHD and/or RHD in their programs, or they may have minimal programming or focus on CHD and RHD.

Connecting with them can help:

- Raise their awareness of CHD and RHD
- Learn about which challenges people living with RHD and CHD share with these larger communities
- Identify policy initiatives designed to address broader community needs that will benefit those living with CHD and RHD

3. Professional societies

Professional organizations such as medical societies can have a major impact on health policy. They can create guidelines and recommendations regarding CHD and RHD care which can guide clinical care and government action. Connections with professional groups often start with an introduction by a member health professional. A partnership with them as experts to support the advocacy messages helps establish legitimacy and trust. There may be opportunities to invite the professional society to endorse, co-sponsor or participate in awareness and educational activities.

4. Government representatives

The ability of organizations and individual citizens to advocate differs from country to country but there are strategies for connecting with policy makers that can work in many different settings. Below are some examples.

- *Invite a government leader to a photo opportunity with patients and families.*
- *Invite a health official to speak or participate in an event.*
- *Seek formal opportunities with the government to offer input on government health initiatives. This might include surveys, meetings, or advisory councils.*
- *Invite health officials or government leaders to be honorary advisors*
- *Connect with a health official or government leader who has been directly impacted by CHD or RHD.*



BUILDING RELATIONSHIPS

Attending events in your area offers opportunity to meet relevant officials. For example, Mended Hearts Zimbabwe's Tendai Moyo introduced herself to a WHO official at a local cancer education event. Her powerful story convinced the WHO to partner with her organization on an education day on CHD.



Belen Blanton, with Venezuela Heart Nonprofit Estrellita de Belen Foundation, met with Venezuelan ambassador Carlos Vecchio

SECTION 3:

Who – Determine Target Audiences

Identify the target audience

Who you are intending to reach with your advocacy efforts for CHD and/or RHD is vitally important to consider when developing your advocacy plan. Knowing your audience, the best methods of communication to reach them and the action you want them to take can significantly impact your success in achieving your goals.

Understand who are the decision-makers

Questions to ask to identify the advocacy audience:

1. Who are the decision-makers and who influences them?
2. What do we need these decision-makers to do?
3. How much impact could they have?
4. What do we know about their current position on the issue? What matters most to them when making decisions?
5. What are the best communications channels to reach the target audience – Internet, television, radio, print, in-person meetings?

Potential advocacy target audiences:

1. Government (ministries and parliament)
 - Presidents and Prime Ministers
 - Health Ministers and their deputies
 - Budgetary decision-makers
(for example: cabinet, Ministries of Finance and Planning)
 - Ministry of Health and other policy makers
 - Elected representatives (Parliament)
2. Medical professional societies
3. The media
4. General public
5. Donors/funding agencies
6. Private sector employers (for example: national and local businesses and business associations and multinationals)
7. Community leaders
8. Nongovernmental or humanitarian organizations

PASSING LAWS

Three US-based organizations came together to draft the Congenital Heart Futures Act, the first law mandating government investment in the long-term well-being of congenital heart patients. The Adult Congenital Heart Association, the Children’s Heart Federation and Mended Little Hearts brought together patients, families and CHD care providers to meet directly with law-makers. Through stories of impact, these individuals highlighted the unmet needs of their community. The legislation passed in 2008 and included the first national registry of CHD patients. Ongoing advocacy has resulted in funding growing from one million in 2009 to 5.5 million in 2021.



The Children's HeartLink Population Health Framework for Heart Disease in Children

The framework looks holistically at the needs of children with heart disease and describes the areas for influence ("What") and the stakeholders that need to be influenced ("Who"). It can guide advocacy activities with different audiences and stakeholders.

	What	Who
Policy & Regulatory Environment	<ul style="list-style-type: none"> • Medical & Postgraduate Medical Education • Capacity Distribution & Planning • Health Financing Schemes • Enabling Technologies & Medicines Availability 	<ul style="list-style-type: none"> • MOH – Medical Service, Public Health, Quality & Safety, HR • MOE – Medical Education Accrediting Organizations • Health Financing Agencies • Professional Health Organizations • Health Research Organizations
Health System Environment	<ul style="list-style-type: none"> • Infrastructure For Service Delivery • Screening & Detection Capacity • Quality Service Standardization 	<ul style="list-style-type: none"> • Sub-national Government Agencies • Screening & Detection Providers • Local Chapters of Professional Health Organizations
Hospital	<ul style="list-style-type: none"> • Clinical Capacity & Quality Outcomes • Organizational Capacity: Leadership & Multidisciplinary Care • Training & Education Capacity • Patient-centered Care 	<ul style="list-style-type: none"> • Pediatric Cardiac Clinicians • Hospital Administrators • Researchers • Medical University Administrators
Interpersonal & Social Networks	<ul style="list-style-type: none"> • Social Attitudes & Norms 	<ul style="list-style-type: none"> • Families of Children with Heart Disease • Community, School, Workplace • Patient & Family Organizations
Individual	<ul style="list-style-type: none"> • Knowledge • Attitude • Skills 	<ul style="list-style-type: none"> • Children with Heart Disease • Families of Children with Heart Disease

SECTION 4:**How – Making and Executing Advocacy Plan and Developing Key Messages****Key messages**

The key messages should be clear, compelling, concise, consistent and convincing, simple and direct and easily reinforced by a combination of sources. They should also be appealing to the target audiences and decision-makers and motivating them to act. They should be developed based on the key messages for advocacy for childhood-onset heart disease in Section 1 and on the contextual research of the country.

Advocacy tools

Advocacy tools are the methods through which to communicate with or influence the target audience by delivering the key messages. To select the most appropriate tools and develop appropriate communication materials, identify how the target audience receives information.

Advocacy tools can be:

- Letters or emails to policy makers and representatives (See Appendix page 2)
- Fact sheets and educational materials with evidence and data to support claims to share with the target audience
- Policy monitoring and analysis
- Publishing and sharing real life CHD/RHD stories and photographs
- Producing research and technical recommendations
- Books/scientific journals/articles and editorials
- Op-eds and other public outlet coverage
- Petitions, letters, signature campaigns
- Sharing relevant messages on a calendar of commemorative health dates
- Teleconferences, phone calls and in person meetings
- Events such as symposia and workshops with invited experts to deliver messages
- Activism and organizing

Using media to communicate the key messages

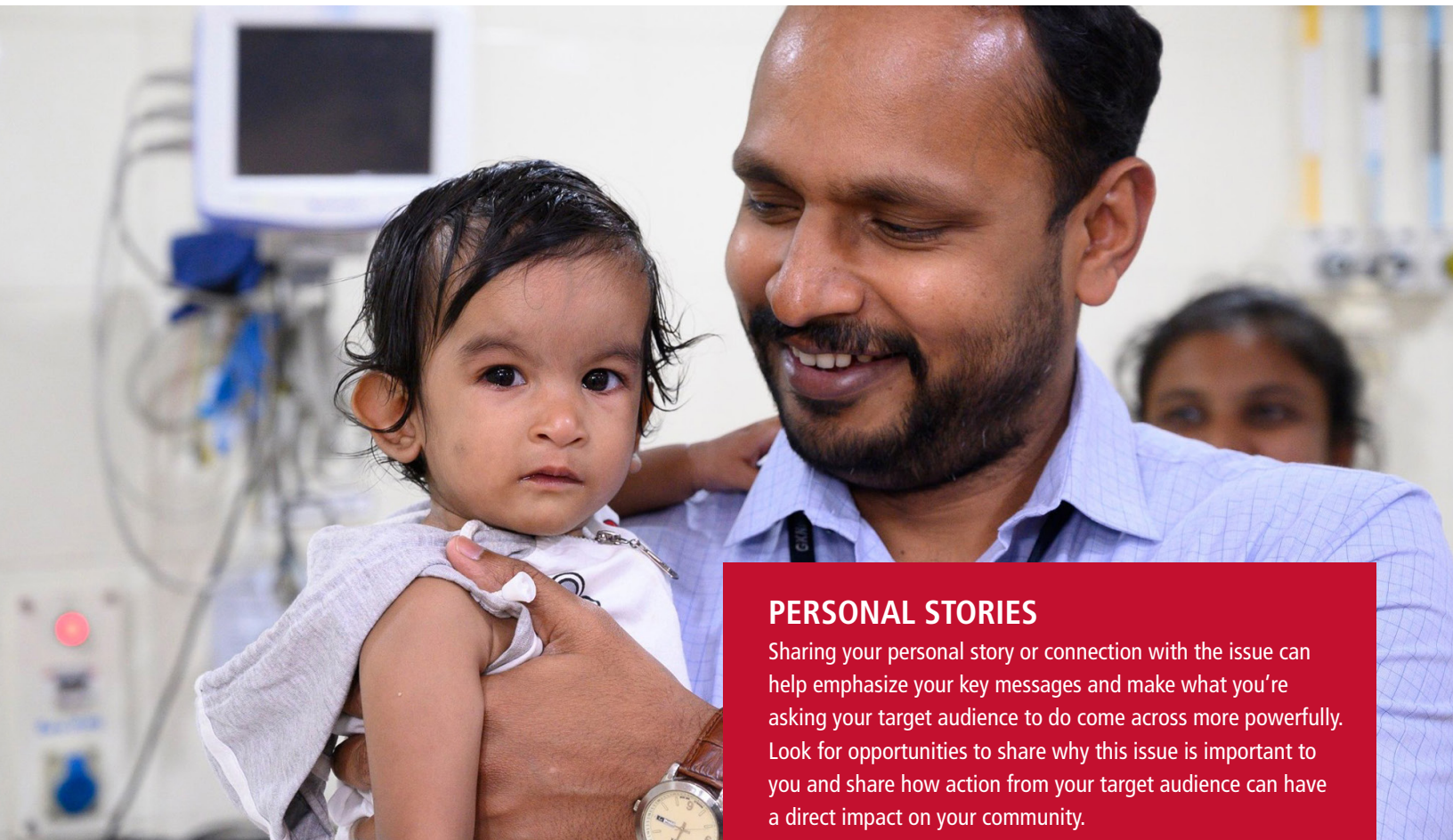
- Both social media and traditional media can be used to spread the messages on a wider scale
- Through social media, advocates can have control over the narrative they wish to convey to others, and posts containing accurate information/facts about the key message can be spread widely
- Build a social media presence also allows to connect with other groups advocating for the same changes/rights
- Use social media platforms by tagging (e.g., policy makers, health organizations) not only when communicating messages, but also with updates and changes/challenges
- Traditional media (i.e. newspapers, television programs) do not allow the same control over the messaging, but guarantee an audience, something simply posting to a social media account cannot
- Maintaining a relationship with the media, producing attractive news stories and running mass media programs will help with building awareness and educating broader audiences. The media can also help decision-makers stay accountable to commitments.

SECTION 4: Continued

Advocacy plan – how to achieve the goal?

The advocacy goal will be best achieved by developing and implementing an advocacy execution plan and timeline which will describe the steps needed to achieve it. An example of a plan:

GOAL: Increase government funding for CHD surgery				
STRATEGY 1: Introduce new policy for financing of CHD care				
ACTION	BY WHOM	BY WHEN	RESOURCES & SUPPORT NEEDED	
1	Meeting with members of parliament	Patients and families	Beginning of government fiscal year	<ul style="list-style-type: none"> • Fact sheet on burden of cost of care • Personal stories and testimonials
2	Social media campaign	Patient and family organizations, professional societies	Months preceding the meeting and after	Create messages to share



PERSONAL STORIES

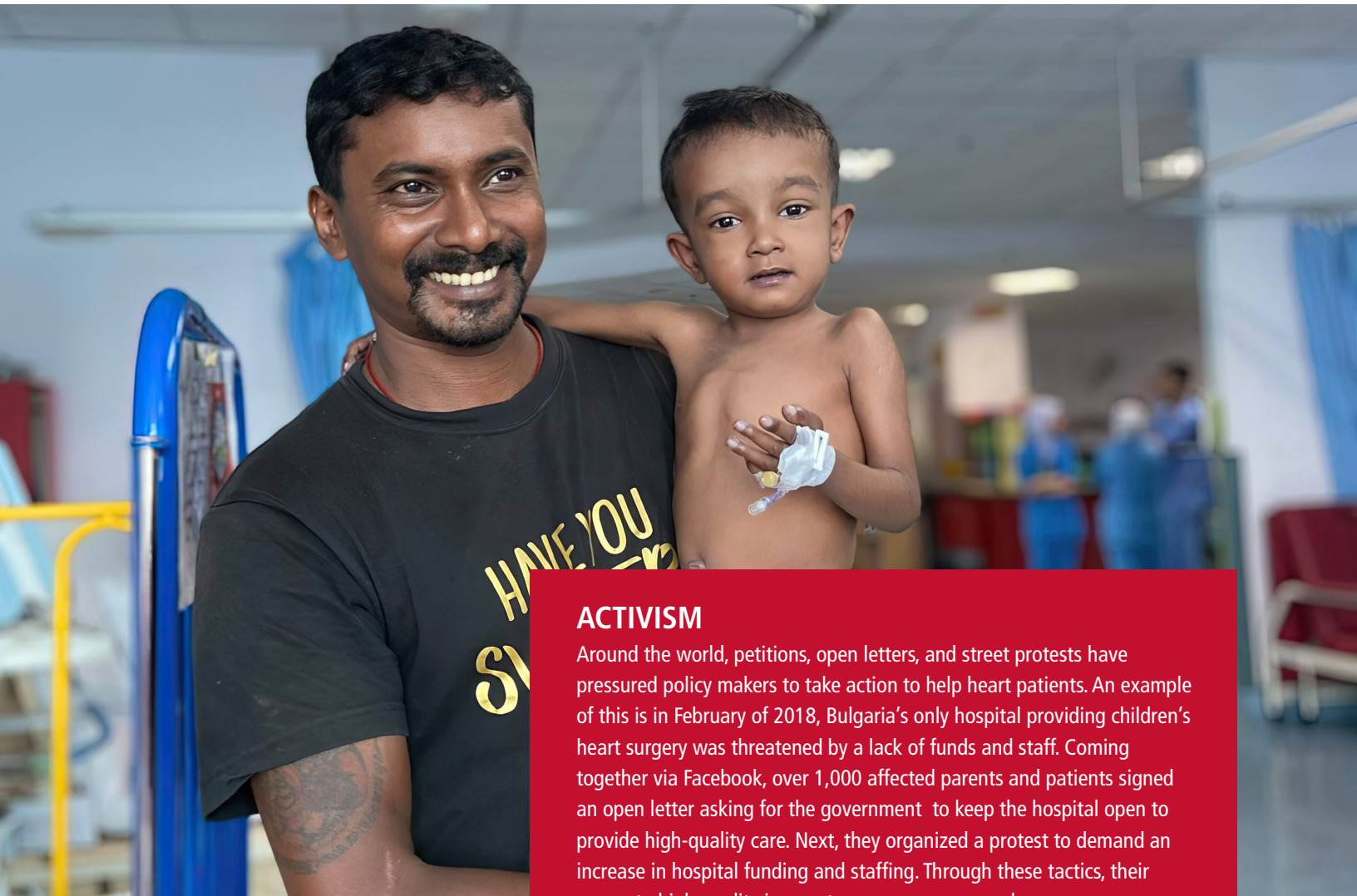
Sharing your personal story or connection with the issue can help emphasize your key messages and make what you're asking your target audience to do come across more powerfully. Look for opportunities to share why this issue is important to you and share how action from your target audience can have a direct impact on your community.

SECTION 5:**How – Measuring Success – Evaluating if the Advocacy Efforts Were Able to Meet the Goal**

While the final goal may be a policy change or social change that will take years to achieve, it is important to understand what the interim successes are. Examples of small successes that contribute to the greater issue include developing a network of people who know and care about the issue, have successful communication with policy makers or a positive reaction through social media campaigns.

An evaluation will include asking questions about the process and outcomes:

- Are the techniques working? How effective are they?
- Are we reaching the target audience?
- Are the target audiences, messages and communications channels still the most appropriate for achieving the goal?
- Is there evidence that the target audiences have changed their attitudes or behavior?

**ACTIVISM**

Around the world, petitions, open letters, and street protests have pressured policy makers to take action to help heart patients. An example of this is in February of 2018, Bulgaria's only hospital providing children's heart surgery was threatened by a lack of funds and staff. Coming together via Facebook, over 1,000 affected parents and patients signed an open letter asking for the government to keep the hospital open to provide high-quality care. Next, they organized a protest to demand an increase in hospital funding and staffing. Through these tactics, their access to high-quality in-country care was preserved.

Appendix

Advocacy Resources

Global ARCH webinars: <https://global-arch.org/learn-more/webinars/>

- Social media for advocacy – <https://youtu.be/39JqNS0lu9U>
- Advocacy examples – <https://youtu.be/36-UuZ5sljg>
- Using the Global Burden of Disease data portal – <https://youtu.be/yIbEe8sMRbE>

Declaration of the Rights of Individuals Affected by Childhood-Onset Heart Disease Toolkit – http://global-arch.org/wp-content/uploads/2021/01/Declaration_Toolkit.pdf

National health plans – typically found on Ministry of Health website

The Global Burden of Disease study – <https://vizhub.healthdata.org/gbd-compare/>

World Bank Data – <https://data.worldbank.org/>

CHL/Global ARCH fact sheets – <https://childrensheartlink.org/wp-content/uploads/2022/02/Congenital-Heart-Disease-Facts.pdf>

The Invisible Child: Childhood Heart Disease and the Global Health Agenda – <https://childrensheartlink.org/the-invisible-child/>

Advocacy Letter Example:

Hello (Representative/Staff),

My name is (enter name). I am a (enter district/town) resident and advocate for _____.

Our mission is to (enter mission).

We would greatly appreciate the opportunity to meet with you to discuss _____ and possible ways to partner with _____ to support children born with and people living with congenital heart disease and rheumatic heart disease. We are available to meet the week of _____ but are flexible. Please let us know if you have any questions, and thank you for your consideration.

Best regards,

(name)

(organization name)

Appendix

Advocacy Toolkit- Sample Meeting Agenda

Introductions

Before you begin your meeting, encourage everyone to introduce themselves by sharing their name and their affiliation with the issue you are here to discuss (example: member of a patient advocacy group; health professional; professional organization). You can also note here any personal connection you bring to this issue. An example introduction is provided below.

Ex: Hello. My name is _____. I'm an advocate with the Global Alliance for Rheumatic and Congenital Hearts. I'm also the parent of a child with congenital heart disease. Thank you for taking the time to meet with our group.

Reason for the Meeting

After everyone has introduced themselves your group leader should state the reason for the meeting. The reason for your meeting should align with your advocacy goal. For example:

We're here to discuss the importance of investments in pediatric cardiac care and to urge you to increase these investments in next year's budget.

Background – Key Facts & Messaging

After you've shared your reason for the meeting, you will want to educate the decision-maker about the issue. Come prepared with key facts and messages about why this issue is important and why a change is needed. Bringing a fact sheet or other supporting documentation to the meeting can help communicate the key messages you want the decision-maker to remember.

Personal Story

Sharing a personal story or connection with the issue you're advocating on makes your ask memorable and helps to build a connection with the decision-maker. Try to connect your personal story with the ask you're making.

Make the Ask

Now is the time to ask the decision-maker to take action in support of your advocacy goal. You should be as specific and time bound as possible when making your ask. For example:

We need your support to increase investments in pediatric cardiac care in next year's budget to (insert amount of funding here). Will you support this request by (insert action you want them to take)?

Ask for Questions

For your advocacy to be effective, it should be an ongoing conversation with the decision-maker. Be sure to pause here and ask if he/she has any questions. If he/she has no questions, you can use this time to ask another question. Example:

Have you had any other advocates speak to you about this issue in the past? Are there other decision-makers you'd recommend our group reaches out to?

Thank You and Follow Up

To end your meeting thank the decision-maker for taking the time to meet with your group. Be sure to confirm the correct contact information to follow up from the meeting.

Appendix

Sources

- Advocacy Toolkit: A Guide to Influencing Decisions That Improve Children's Lives. UNICEF, 2010, <https://www.right-to-education.org/sites/right-to-education.org/files/resource-attachments/UNICEF%20Advocacy%20Toolkit.pdf>
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Global ARCH

The mission of the Global Alliance for Rheumatic and Congenital Hearts (Global ARCH) is to improve worldwide lifelong outcomes in childhood-onset heart disease through empowering patient and family organizations. Membership is free and open to any group that serves patients with congenital and/or rheumatic heart disease and their families. Our alliance brings together organizations from around the world to learn, collaborate, and speak out together about the unmet needs of those living with childhood-onset heart conditions.

Children's HeartLink

The mission of Children's HeartLink is to save children's lives by transforming pediatric heart care in underserved parts of the world. Children's HeartLink has over 50 years of experience working in low- and middle-income countries to build capacity and advocate for quality pediatric cardiac care.

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