




Prescription for Life: Take action to help children living with HIV



The vast majority of children living with HIV around the world lack access to HIV testing and treatment. We can do something about that. The Ecumenical Advocacy Alliance (EAA), in collaboration with partners around the world, is embarking on a year-long action with governments, pharmaceutical companies and media to improve access to medicines for children with HIV. Children and young people are invited to take action with their school, faith community or family to help make this happen.

This action guide builds on the EAA's teaching resource on advocacy and HIV and AIDS, which is available for fuller information about teaching children about AIDS and advocating for progress in prevention, treatment, care and support: <http://www.e-alliance.ch/keep-the-promise/>

What you can do!

This action guide is for teachers and schools, parents and families, faith leaders and their communities, and all who play a vital role in making young people more aware of the world in which they live and empowering them to take action on behalf of, and in solidarity with, others.

Young people, especially aged 11-16, are encouraged to write letters to governments and pharmaceutical companies asking them to improve the treatment and services available to children living with HIV. Ideas are also given for students and youth groups to raise awareness of these issues in local newspapers and other media.

Plans for three activities for youth groups, schools and families are included:

- learning about children and HIV
- writing letters to government health ministries and pharmaceutical companies
- gaining media coverage of letter writing activities and of the issues.

The EAA plans to display copies of young people's letters at the United Nations on the 20th anniversary of the Convention on the Rights of the Child, which will be celebrated on Universal Children's Day - 20 November 2009. See page 3 for details of where and when you should send your letters.



Action Step 1: Learning about children and HIV

Before young people write their letters, talk with them about HIV and AIDS and, particularly, access to medicines for children living with HIV. The information and resources in this guide and online at <http://www.e-alliance.ch/accessmeds/children> can help.

Share personal stories about children living with HIV – perhaps a child living with HIV who is not receiving the medicines they need and another HIV-positive child who is. Talk about the

differences in the stories. Try to include some information about children living with HIV in your country and any issues they face with access to medication.

Children will probably want to know how babies and children get HIV, and they may ask how they avoid getting HIV. Resources are available online to help you talk about HIV prevention with children and youth.

Talk about the important role of pharmaceutical companies in the research and development of medicines. Explain how the pharmaceutical companies have discovered medicines such as aspirin and penicillin and how millions of lives have been saved by these discoveries.

Speak to young people about the United Nations Convention on the Rights of the Child. Governments have committed themselves to doing everything they can to give children the best health care possible. We need to remind them of their responsibilities.

Stories and other information on all these areas can be found at: <http://www.e-alliance.ch/accessmeds/children>



Action Step 2: Putting pen to paper

Tell young people why campaigning is worth the effort: their letters, along with thousands of others from around the world, will be read by influential people in pharmaceutical companies and in government. These people have real power to make a difference for hundreds of thousands of HIV-positive children who have little or no access to medicine. Young people's letters will also go on display at the United Nations and other international centers to remind people of the importance of making medicines available to children living with HIV.

Young people should handwrite their own letters to their government health ministry and the pharmaceutical company selected (see <http://www.e-alliance.ch/accessmeds/children>). Not all the letters should be the same. Use the sample letters as a general guide but encourage young people to use their own words (and even their

own drawings) and to think about what concerns them personally. Suggest that young people include any particular issues relevant to their country. They may also have their own ideas about what action they think pharmaceutical companies and health ministries could take. There might be a specific question they want to raise, or a personal story they want to tell. Young people should thank the government for any HIV initiatives they have taken, in particular to improve access to medicines for HIV positive children.

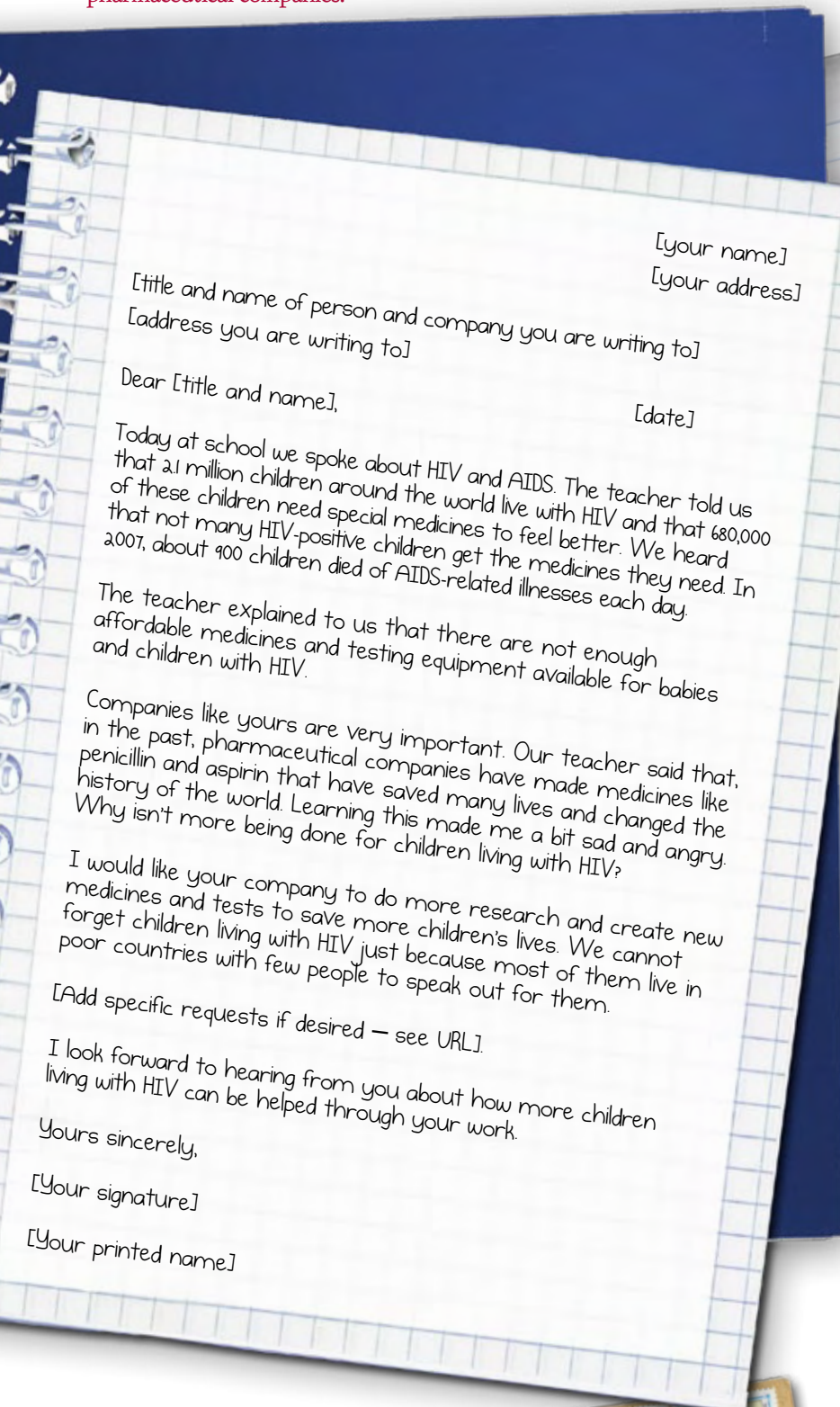
You will need:

- Information on children living with HIV, testing and treatment for pediatric AIDS, and the Convention on the Rights of the Child
- Name and address of Minister of Health.
- Postage (letters to pharmaceutical companies should all be sent to the EAA in Geneva; letters to the Minister of Health should be sent directly to the government, with a copy of one or two letters sent to the EAA).
- Information on specific requests for certain pharmaceutical companies (see <http://www.e-alliance.ch/accessmeds/children>).
- Pens and paper



Letters to pharmaceutical companies

Aim: To improve access to pediatric HIV testing and treatment through letters written by young people, to a target group of pharmaceutical companies.



[your name]
[your address]

[title and name of person and company you are writing to]
[address you are writing to]

Dear [title and name],

[date]

Today at school we spoke about HIV and AIDS. The teacher told us that 2.1 million children around the world live with HIV and that 680,000 of these children need special medicines to feel better. We heard that not many HIV-positive children get the medicines they need. In 2007, about 900 children died of AIDS-related illnesses each day.

The teacher explained to us that there are not enough affordable medicines and testing equipment available for babies and children with HIV.

Companies like yours are very important. Our teacher said that, in the past, pharmaceutical companies have made medicines like penicillin and aspirin that have saved many lives and changed the history of the world. Learning this made me a bit sad and angry. Why isn't more being done for children living with HIV?

I would like your company to do more research and create new medicines and tests to save more children's lives. We cannot forget children living with HIV just because most of them live in poor countries with few people to speak out for them.

[Add specific requests if desired – see URL]

I look forward to hearing from you about how more children living with HIV can be helped through your work.

Yours sincerely,

[Your signature]

[Your printed name]



Where and when should you send your letters?

Government letters:

Please send government letters directly to your Minister of Health and send copies of some of these letters to the EAA at:

Ecumenical Advocacy Alliance
P.O. Box 2100
150 route de Ferney
1211 Geneva 2
Switzerland

Pharmaceutical companies:

Please send the EAA your original letters to pharmaceutical companies. The EAA will send them on and follow up with companies on specific requests regarding medicines and diagnostic tests.

Deadline:

Letters should arrive in Geneva by September 2009 to be included in the exhibit and used in EAA advocacy meetings with companies. If you cannot meet this date, please still send your letters to keep up the pressure on pharmaceutical companies and governments.



Letters to Ministers of Health

Aim: To ask Ministers of Health to fight inequality and injustice affecting HIV-positive children who are not receiving treatment, and to ensure these children receive their rights to medicine and testing.

Sample letter to government Minister of Health

All governments of the world, except for the United States of America and Somalia, have ratified or acceded to (formally agreed and adopted) the United Nations Convention on the Rights of the Child (CRC). If you write to the USA or Somalia, you may want to ask them why they haven't done so and suggest they ratify the CRC.

Action Step 3: Gaining media attention

Aim: To gain media publicity of young people's letter-writing and, through this, to publicize the issue of access to testing and appropriate treatment for children living with HIV.

Spreading your message

Gaining media coverage of your letter-writing spreads the message of access to pediatric HIV medicines across your whole community. Maybe others will join you in lobbying your Minister of Health and pharmaceutical companies too.

When you approach the media you'll be competing with all the other stories going on that week. Discuss with the young people, ideas to make your story stand out. How about putting on an event to launch your letter-writing activities? There are good ideas in the accompanying online material at: <http://www.e-alliance.ch/accessmeds/children>. The Keep the Promise teaching resource on advocacy and HIV and AIDS also gives good tips for gaining media coverage: <http://www.e-alliance.ch/keep-the-promise/> Here are a couple of ideas to get you started:

- ✿ Write a giant letter as a publicity stunt and get people to sign the bottom of it - including a local celebrity or two.
- ✿ Put on an event in your school, local church or community hall to raise awareness of issues surrounding access to HIV medicines for children. You could host a music concert by the youth, run a talent contest, a car wash, a sponsored walk, write stories on the issue, perform public readings... anything creative you can think of.

Sample letter to government Minister of Health

[your name]
[your address]

[title and name of person you are writing to]
Ministry of Health
[government address]

[date]

Dear [title and name],

There are around 21 million children living with HIV around the world but hardly any of these children receive medicine. In 2007, about 900 children died of AIDS related illnesses each day.

In 2009, we will celebrate the 20th Anniversary of the Convention on the Rights of the Child. As part of this, our government promised to do its best to make sure all children in our country receive health care (article 24). This is not happening. It is very difficult to find out if a baby has HIV because there are few HIV tests available for small children. Also, there are not enough affordable and usable HIV-medicines made for babies and children.

Therefore I, along with many other children around the world, am writing to my government to ask you to keep the promises you have made to ensure that HIV-positive children receive the medicines they need. [Add your suggestions and questions on this issue].

Thank you for all that you are doing already for children living with HIV and AIDS. Please let me know what other plans you have to make it possible for all HIV-positive children to receive healthcare. Also, please let me know how I can help you in our country's response to the AIDS epidemic. I look forward to hearing from you soon.

Yours sincerely,

[your signature]

[your name]

Tips for approaching the media

The best way to inform the media about your letter writing is with a press release. Call your local newspaper or radio station and find out to whom you send press releases. In the release, give some key facts about the issue and include a quote from a young person about why they are writing the letters. Give contact details of a key person in your school/group who will be acting as spokesperson to the media. Follow your press release up with a phone call a few days later to check that the press release has been received and to see if the story will be covered. See a sample press release at

<http://www.e-alliance.ch/accessmeds/children>

Children and HIV

Today it is estimated that 2.1 million children¹ around the world are living with the Human Immunodeficiency Virus (HIV). Yet children remain largely forgotten in global and national efforts to address HIV and AIDS. This is especially the case for children's access to diagnostic testing for HIV and medicines to treat HIV, known as antiretrovirals (ARVs). Currently, only 15 percent of children in need of HIV treatment have access to it.

Most children living with HIV were infected through their mothers. If a woman living with HIV has a child, the child may be infected during pregnancy, childbirth or breastfeeding. However if the woman can get the proper care and treatment the chance of passing on the virus can be reduced to 2 in 100.

HIV is extremely aggressive in children's small bodies. When children living with HIV do not get appropriate treatment, they suffer and die faster than adults living with the virus. Despite evidence that HIV treatment is very successful in children, more than 900 children die of AIDS-related illnesses every day. One of the most common AIDS-related illnesses is tuberculosis (TB). Children are at higher risk than adults from TB.

The challenges

- While services and treatment exist to prevent mother-to-child transmission of HIV, only about one-third of women globally have access to them.
- Currently it is difficult to diagnose HIV in infants because there is limited testing available to make diagnoses in children under 18 months of age.
- Only a few ARVs are suitable for children, especially those under two years old. These are often very expensive and are not sold in all countries.

¹Children in this context are those under 15 years of age.

- In particular, there is an urgent need for ARV medicines for children that combine all the medication they need each day in one pill. These are known as fixed dose combinations and are needed to treat HIV on its own and to treat children with both HIV and TB.
- In countries where health systems have very little money or skilled staff, particularly staff trained in pediatric AIDS, children living with HIV struggle to get treatment.

To find out more about the challenges surrounding treatment for children living with HIV, visit

<http://www.e-alliance.ch/accessmeds/children>

The response

Advocacy on children's access to HIV treatment has made a real difference already: the number of HIV positive children receiving treatment has increased by over 150 per cent in two years. In developing countries, almost 200,000 children received treatment for HIV in 2007 compared with 75,000 in 2005. Yet, especially in Africa, there is still a long way to go. All children living with HIV have the right to diagnosis and child-friendly medications, so we need to keep the pressure on governments and pharmaceutical companies to provide this.

In 2008, the world celebrates the 60th Anniversary of the Universal Declaration of Human Rights and, in 2009, the 20th Anniversary of the Convention on the Rights of the Child. Both of these international legal agreements recognize the child's right to health.

We need to call on political leaders to fulfill their obligations to do all they can to protect the health of all children including those living with HIV. We also need to pressure pharmaceutical companies to research and develop new tests to detect HIV in infants and new ARVs suitable for infants and children. These medicines need to be produced in fixed dose combinations, and must be available and affordable in developing countries. Young people in particular can make an impact on governments, companies and media to make this happen.

There is more information about the issues facing children living with HIV, and this letter-writing action, at:

<http://www.e-alliance.ch/accessmeds/children>

We'd like to recognize your efforts!

It is the combined efforts of young people around the world that could really make the difference for children with HIV. In recognition of this, we will award a certificate to each group that sends us feedback about their activities, along with a copy of one or more of their letters. See page 3 for details of where and when to send your letters.



Useful sources of information

- The 2008 report on the Global AIDS Epidemic at http://www.unaids.org/en/KnowledgeCentre/HIVData/GlobalReport/2008/2008_Global_report.asp
- Avert - an international AIDS charity with a section just for teens at <http://www.avert.org>
- The World Health Organization at <http://www.who.int/hiv/topics/paediatric/en/index.html>
- The Elizabeth Glaser Pediatric AIDS Foundation at <http://www.pedaids.org>

Resources on HIV and AIDS, and advocacy

- The Ecumenical Advocacy Alliance at www.e-alliance.ch
- The EAA teaching resource on advocacy and HIV and AIDS at <http://www.e-alliance.ch/keep-the-promise/>
- The UNICEF global campaign Unite for Children, Unite against AIDS at <http://www.uniteforchildren.org/index.html>



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Other campaign actions to get involved in:

- UNICEF Guide to Action (an advocacy tool for children): http://www.unicef.org/knowyourrights/discuss_guide.html
- World Health Organization Make Medicines Child Size campaign: <http://www.who.int/childmedicines/en/>
- Global Action for Children campaigns for rights and commitments to be met for orphans and vulnerable children in the developing world: <http://www.globalactionforchildren.org>

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Your group can receive a certificate to recognize your efforts. Fill in this form and send it to the EAA with your letters to pharmaceutical companies, and/or copies of one or more letters to your country's minister of health (see page 3).



Name of group (as it should appear on the certificate): _____

Mailing address: _____

Country: _____ Contact name: _____

Phone number: _____ E-mail address: _____

More information on your action

How many young people were involved? _____

What went well? _____

Any problems? Please describe. _____

If possible, please send a photo of your group taking part in the activity, and let us know of any responses you get from companies or your government and any media coverage of your actions. Our contact details are on this page.