

PARENT ADVOCATE TOOLKIT

INTRODUCTION

Voices for Vaccines is a parent-led organization that supports and advocates for on-time vaccination and the reduction of vaccine-preventable disease. While a majority of parents choose to immunize their children against disease, vocal opposition to vaccines is compromising immunization rates across the country and causing vaccine preventable diseases to reemerge - the anti-vaccine movement is endangering our families.

The loudest voices in the vaccine discussion are those who are opposed to vaccination and we believe this has to change – and that change starts when parents who immunize add their voices to the conversation. To truly protect our kids, and other vulnerable members of our community, we need to go beyond vaccinating our own children on schedule and start battling the myths and misinformation surrounding vaccines.

We created this toolkit because we know that peer-to-peer influence is powerful. Research has shown that the people in a parent's life play an important role in that parent's decision to vaccinate. This toolkit will provide evidence-based information about the safety and importance of immunization and help prepare you in your role as a parent advocate.

You can share the information provided in this toolkit with confidence, knowing that the contents have been reviewed and approved by the Voices for Vaccines Scientific Review Board:

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1 <http://pediatrics.aappublications.org/content/early/2013/04/10/peds.20122452>

VoicesForVaccines.org

ABOUT THE PARENT ADVOCATE TOOLKIT

Voices for Vaccines developed this scientifically accurate toolkit to help parents become a voice of reason amidst a cacophony of conflicting vaccine discourse. You will be provided with reliable information about vaccines and the answers to some of the common concerns about vaccine safety.

WHY PARENT-LED ADVOCACY?

Parents turn to other parents for advice on childbirth, for tips to soothe a fussy baby, or to find the best brand of bottles. It is even how many of us choose our child's healthcare provider. The myths of the anti-vaccine movement are spread through compelling stories in this environment, and it is more important than ever to correct those dangerous tales.

Loving parents may be persuaded to question why their newborn really needs so many shots, or if vaccines are safe at all, despite the overwhelming medical evidence for vaccine safety. At Voices for Vaccines, we believe it's time for parents who vaccinate to begin sharing their stories and telling the world why they choose to protect their children from vaccine-preventable diseases.

Some reasons that parents avoid speaking up about vaccines are:

- We have not realized how another person's decision to vaccinate actually affects our family. Many parents vaccinate their children without concerning themselves with the decisions of others, but as vaccination rates continue to drop, diseases can make their way back into our communities and our families are put at risk. It is more important than ever to speak up.
- We don't want to offend our friends, or involve ourselves in another family's parenting decisions. While this is likely sage advice when it comes to the many private decisions a family makes about how to best raise their children, vaccination is not a personal choice - it affects everyone. Our objective is to empower you to educate and inform others in order to protect your family and your community.

- Vaccine science is complicated, and if you do not have a medical or scientific background it may be difficult to know what to say when you hear misinformation. Our goal is to equip you with the basic facts about vaccines safety and effectiveness, and truths behind some of the most common vaccine myths. You will also learn some tips about how to respond to difficult questions.

HOW TO USE THE TOOLKIT

This toolkit is designed to help you to plan and host a community vaccine awareness event by:

- Providing essential facts and talking points about vaccines
- Providing a visual slideshow that can supplement your presentation
- Helping you answer difficult questions
- Offer recommendations of reputable sites for more information
- Help with the logistics of planning an awareness event
- Suggesting tips to motivate others to become vaccine advocates, and
- Creating assessment tools to measure the success of your efforts

STEP 1

Read the entire toolkit, the supplemental fact sheets, view the visual slideshow and the provided resource links to establish a sound base of knowledge that can help you encourage on-time vaccination and motivate other parents to speak up for vaccination.

STEP 2

Use the toolkit to plan and host a community awareness event. Your event will serve to inform your peers about the importance of vaccinations, the safety and efficacy of vaccines, and the need for vaccine advocacy among other parents. Your event can be large or small.

STEP 3

At the conclusion of your event, use the surveys to collect information about the impact of your outreach. Completing the surveys is important because the feedback will help improve future events, and submitting the data to Voices for Vaccines will help us enhance our resources. Pictures are great too!

PARENT ADVOCATE PRESENTATION GUIDE

This guide will assist you in delivering your community presentation. Follow the sample scripts below to engage your audience while you discuss the importance of vaccination. This guide can also encourage participants to use the facts they learn to become vaccine advocates.

WELCOME

“My name is _____. I am a parent, a vaccine advocate, and a member of Voices for Vaccines. I would like to start by telling you why I am involved in this cause.”

Tell your personal story about why vaccinating on schedule is important to you. Your audience will appreciate your heartfelt reason for caring about vaccines.

“Thank you for joining me for this important discussion. The objectives of this presentation are to learn (1) some important facts about vaccines that will help you make important family health decisions; (2) the truth behind several dangerous vaccine myths and how to protect your community by responding to misinformation.”

VISUAL PRESENTATION

This toolkit includes a Parent Advocate visual presentation. The slideshow contains key messages from the “Safe and Effective: Vaccines Work!” handout and the “Vaccines are Important” fact sheet and can serve as a supplement to your presentation. Attendees may ask questions during or at the end of your presentation so it is strongly recommended that you have a physician or public health official present.

GOALS AND CENTRAL MESSAGE

The goals of your outreach are to:

1. Educate participants on the importance of vaccines so that they can make the family health decision to vaccinate on schedule
2. Inform participants on the facts behind several common vaccine myths so that they will be more likely to respond to misinformation.

The central message is:

1. Vaccines are safe and effective.
2. On-time immunization is crucial for keeping our communities and our families free from preventable diseases and the suffering and complications they bring.
3. The anti-vaccine movement is putting our families and our community in danger. The choice not to vaccinate affects everyone.

CLOSING AND CALL TO ACTION

- Today we have learned that vaccines are safe and effective.
- The anti-vaccine movement is putting our families and our community in danger. Vaccination is not a personal choice - it affects everyone.
- Now that you know the truth about vaccines, you can respond to dangerous misinformation when you hear it or see it posted on social media.
- You can sign up to be a member of Voices for Vaccines and become a parent advocate at www.VoicesForVaccines.org

SAMPLE AGENDA

Follow this sample agenda to help your event run smoothly; feel free to alter the schedule to fit your needs and your audience.

- | | | |
|-----|--------------------------------|---|
| I | Welcome and Introduction | Your welcome message |
| II | Identify the goals of outreach | Communicate central message
Summary of agenda |
| III | Distribute Materials | Hand out fact sheet on the importance of vaccines, fact sheet on the facts about vaccines, fact sheet on where to get more information |
| IV | Presentation & Discussion | Use the discussion guide and optional visual presentation to communicate key points.

Attendees can ask questions during or at the end of the presentation, and it is strongly recommended that you have a physician or public health official present. |
| V | Call to Action | Summarize message on vaccines being safe and effective
Summarize why vaccines are everyone's business
Encourage participants to use the facts they learned to become vaccine advocates |
| VI | Adjourn | Thank participants |

TALKING POINTS FOR “SAFE AND EFFECTIVE: VACCINES WORK!”

This serves as a presenter’s supplement to the fact sheet “Safe and Effective: Vaccines Work!”

These are the main points that you should communicate to your audience during “The Truth About Vaccines” portion of your presentation. When you answer questions, consider these facts when you construct your answer.

- 1. Vaccines work with your natural immune system.** Vaccines trigger the same immune response that a germ might trigger, but do not cause illness. While the body is fighting off these antigens, it creates memory cells that will be able to defeat future invasions of a more potent wild disease. In this way, vaccines are quite natural.
- 2. Vaccines are a healthy choice.** Vaccines do not cause chronic illness and they do not compromise or weaken the immune system. They do protect against dangerous diseases and can prevent or reduce hospitalization, long-term illness, suffering, and death. The current vaccination schedule was developed to protect children at the times they are most vulnerable to certain diseases.
- 3. A baby can safely handle vaccines.** The entire childhood schedule contains 150 antigens (antibody-stimulating substances) that present a challenge to a child’s immune system -- and due to the advancements in vaccine technology this is significantly less than what we received as children, even though we were vaccinated against fewer diseases. Each day, a child’s immune system faces up to 6,000 pathogens -- It can handle a few from vaccines without problem. Delaying a vaccine offers no benefits and simply leaves a child susceptible to preventable illness for a longer period of time.

4. Vaccine ingredients are safe. Vaccines are rigorously tested. In order for a vaccine to be licensed it must be proven safe and effective. The ingredients are not nearly as strange or scary as they sound, and the amounts of these ingredients are easy for the body to handle and pose no health risk to children or adults. It's important to know that vaccines contain miniscule amounts of what they do contain - just enough to do the job they are meant to do. What is unsafe is leaving children vulnerable to disease. In comparison, the benefits of vaccines far outweigh the minimal risks they pose.

5. Vaccines Work. An honest look at the number of cases of a disease before vaccines shows that these diseases were a menace until after the vaccine was licensed. Sometimes, the death rate from a disease declined before a vaccine was licensed, but the disease continued to cause illness, suffering, and disability at unacceptably high rates. And while death rates may have declined, people still died. Preventing disease has, in some cases, eliminated deaths in areas where the vaccines are used.

6. Vaccination is everyone's business. While vaccines are extremely effective they do not work perfectly so when someone chooses to not vaccinate, that choice can affect all of our children, especially those who are immunocompromised or too young for certain vaccines. Vaccinating is a socially conscious choice, and we care about immunizations because we care about our communities.

TALKING POINTS FOR “VACCINES ARE IMPORTANT!”

This serves as a presenter's supplement to the fact sheet “VACCINES ARE IMPORTANT”

These are the main points that you should communicate to your audience during “The Importance of Vaccines” portion of your presentation. When you answer questions, consider these facts when you construct your answer.

1. Vaccines have been tested extensively, and are proven to be^{1,2} safe and effective.

2. While vaccines do come with some risks³, most side effects are mild such as soreness at the site of the injection. The risk of developing complications from a preventable disease is far greater than the risk of having a serious adverse reaction from the vaccine.

3. Vaccines are extremely effective at preventing disease, but like all medicines, they do not come with a 100% guarantee. It is important to maintain high vaccination rates in the community so that everyone is protected.^{4,5}

4. The choice to vaccinate affects the entire community. When a family chooses to not vaccinate they not only put their children at risk of vaccine preventable disease but they also jeopardize the safety of others⁶. This includes: infants too young to be vaccinated, pregnant women and their unborn babies, the immunocompromised, those that cannot be vaccinated, and the small percentage of healthy vaccinated children whose vaccine was not 100% effective.

¹ <http://www.cdc.gov/vaccines/parents/infographics/journeyofchildvaccine.html>

² <http://www.historyofvaccines.org/content/articles/vaccinedevelopmenttestingandregulation>

³ <http://www.cdc.gov/vaccines/vacgen/6mishome.htm#risk>

⁴ <http://pediatrics.aappublications.org/content/early/2013/09/24/peds.20130878>

⁵ <http://www.niaid.nih.gov/topics/pages/communityimmunity.aspx>

⁶ <http://www.voicesforvaccines.org/category/immunocompromisedchildren/>,
<http://www.citypages.com/20090603/news/rarehibdiseaseincreasesinMinnesota/>,
<http://www.cdc.gov/mmwr/preview/mmwrhtml/mm5708a3.htm>

RELIABLE MEDICAL INFORMATION

If you do not know the answer to a question, refer participants to one of these websites or books. Medical questions should only be answered by a healthcare professional.

Websites:

Immunization Action Coalition: www.vaccineinformation.org

Immunize for Good: www.immunizeforgood.com

Vaccine Education Center:

www.chop.edu/service/vaccine_education_center/home.html

National Network for Immunization Information:

www.immunizationinfo.org

Vaccinate Your Baby: www.vaccinateyourbaby.org

Centers for Disease Control and Prevention: www.cdc.gov/vaccines

American Academy of Pediatrics: www2.aap.org/immunization

The History of Vaccines: www.historyofvaccines.org

Books:

- *Deadly Choices: How the Anti -Vaccine Movement Threatens Us All,* by Dr. Paul Offit
- *Your Baby's Best Shot: Why Vaccines Are Safe and Save Lives,* by Stacy Mintzer Herlihy and E. Allison Hagood
- *Baby 411: Clear Answers & Smart Advice For Your Baby's First Year,* by Denise Fields and Dr. Ari Brown
- *What to Expect Guide to Immunizations,* by Heidi Murkoff and Sharon Mazel
- *Do Vaccines Cause That?! A Guide for Evaluating Vaccine Safety Concerns,* by Dr. Martin G. Myers and Diego Pineda
- *The Panic Virus: A True Story of Medicine, Science, and Fear,* by Seth Mnookin
- *Autism's False Prophets: Bad Science, Risky Medicine, and the Search for a Cure,* by Dr. Paul Offit
- *Your Baby's First Year,* by The American Academy of Pediatrics
- *Taking Care of Your Child: A Parent's Guide to Complete Medical Care,* by Robert Pantell, James Fries, Dr. Donald Vickery, Dr. James F. Fries, Dr. Donald M. Vickery, Dr. Robert H. Pantell

ANSWERING QUESTIONS

Vaccination concerns our children, so it can be an emotional topic and may elicit heated debates. As a parent advocate, it is important that you maintain your credibility so when someone asks a difficult question

- (1) stay on point and stick to the talking points, and
- (2) direct specific medical questions to a health care provider.

When someone asks a question that you do not have the answer to, it is fine to say you don't know, and that you can either find out or direct them to a health care provider or the list of websites on the Reliable Medical Information factsheet.

EXAMPLES OF DIFFICULT QUESTIONS AND HOW TO RESPOND

Tip: You can practice these by referring to your educational materials, resource links, and talking points before looking at the sample answers.

1. My friend's vaccinated kid got pertussis. Why would I give my child the vaccine if they clearly don't work?

SAMPLE ANSWER: First, In order to be licensed a vaccine must be proven safe and effective, so the best way to protect your child is to have them vaccinated.

Now, there are a number of reasons your friend's children could have still caught pertussis. The pertussis vaccine works fine in infants and children 2-3 years after they receive it, after which immunity begins to wane.

Vaccinating mothers during the third month of pregnancy is critical to giving infants a head start with their immunity. With enough people vaccinated, the disease would be less likely to catch hold in a community.

2. I understand vaccinating for some things, but what about chickenpox? We all had this as children and it isn't a serious disease.

SAMPLE ANSWER: The benefits of vaccines far outweighs the minimal risk so there is never reason to take a chance with a natural infection that can cause your child to suffer, enter the hospital, or can cause death.

In the United States, every year before we had a chickenpox vaccine, there would be approximately 10,000 people who would be hospitalized with chickenpox.

Chickenpox virus would infect the lungs, it would infect the brain, and the blisters would become infected with bacteria. And every year, about 100 people would die from chicken pox. Most of those people were previously healthy, many of those people were children¹.

3. Why would I give my baby the Hepatitis B vaccine? I don't have hepatitis, so giving her that shot right at birth seems ridiculous.

SAMPLE ANSWER: The current vaccination schedule was developed to protect children at the times they are most vulnerable to certain diseases. Delaying a vaccine offers no benefits and simply leaves a child susceptible to preventable illness for a longer period of time.

In the case of Hepatitis B, many adults do not know they have it -- adults who may have contact with your baby. Infants are at special risk because if they become infected at birth, 90% of them will develop a life long hepatitis B infection and 25% of those will develop liver cancer or liver failure later in life.

This² serious disease can be spread casually through things like washcloths and toothbrushes³, and 15% of people who contract Hepatitis B never discover the source of their infection⁴.

It is especially important to protect baby as soon as possible.

4. I know a friend whose baby was fine until he was vaccinated, and now he's autistic.

SAMPLE ANSWER: I understand why a parent who thought their child was fine before a vaccine and noticed their child showing symptoms of autism after the vaccine would ask if the vaccine could have caused it.

The good news is that that question has been answered. The correlation between vaccines and autism has been thoroughly studied and there are numerous examples of consistent evidence showing that vaccines do not cause autism.

The early signs of autism are difficult to detect and often go unnoticed by parents and pediatricians until a child is at the age when he or she receives certain vaccines.

To get that answer about vaccines and autism, we have to look at the population-level. If vaccines caused autism, we would find that children who were not vaccinated were less likely to be autistic. However, studies have shown that being vaccinated does not change the likelihood of being autistic. Instead, all the best research points to autism having a genetic cause and beginning in the womb.

1 <http://www.chop.edu/service/vaccineeducationcenter/lookateachvaccine/varicellachickenpoxvaccine.html>

2 <http://www.immunize.org/catg.d/p4090.pdf>

3 <http://www.chop.edu/service/vaccineeducationcenter/lookateachvaccine/hepatitisbvaccine.html>

4 <http://www.immunize.org/catg.d/p4090.pdf>

EVENT PLANNING GUIDE

HAVE A SUCCESSFUL EVENT

Your successful event can be large or small; you can host a small private party in your home or you can partner with another organization and hold a large community event. This toolkit will provide you with the resources you need to inform and motivate your peers.

To reach a larger number of people, consider the audience you intend to target and develop a collaborative partnership with another group such as your local health department, a doctor's office, a local health advocacy group, or your children's school. Invite an expert, such as a physician or public health official, so you have someone on hand who is qualified to answer medical questions. Use the checklist to make sure you are prepared and consider taking photos to send to Voices for Vaccines (email them to info@voicesforvaccines.org).

CHECKLIST

- Consider joining forces with a friend or colleague, or form a small committee of concerned parents to plan an outreach event
- Determine a date and time for your event
- Select a meeting place. This can be a home, library, doctor's office, health department, or municipal meeting room.
- Determine how you want the room set up. Do you want people to sit in a circle or in rows? Ensure you have the adequate number of tables and chairs and that all audio-visual needs are met.
- Print any materials, such as fact sheets, that you wish to provide
- Determine how you want to publicize your event. Facebook? Community Calendar? News Release?
- Other _____

MEDIA

If you are planning a large, community wide event, the media can be an excellent way to promote your outreach.

- Consider sending a press release to local newspapers and news stations. It should contain the "who, what, when, where" details and should be distributed at least one week before your event. A sample is provided in the toolkit.

- If you partner with another organization be sure to discuss all media outreach and consider writing a joint press release -- health departments, universities, or other large organizations may have their own communication department that can help write and disseminate the information.
- Follow up with news outlets two days before your event.
- Be prepared when the media arrives at your event. If you are interviewed be sure to stick to the key talking points:
 1. Vaccines have been proven safe and effective.
 2. On-time immunization is crucial for keeping our communities and our families free from preventable diseases and the suffering and complications they bring.
 3. The anti-vaccine movement is putting our families and our community in danger of vaccine preventable disease. Vaccinating our children is a socially conscious choice and the choice to not vaccinate affects everyone.

THANK YOU

Thank you for dedicating your time and talents to advocate for on-time vaccination! If you have any questions about this toolkit or if you need any assistance, we are available to help you. Please contact Voices for Vaccines at info@voicesforvaccines.org.

SAMPLE PRESS RELEASE

<Name>

FOR IMMEDIATE RELEASE

<Phone Number>

<Email Address>

LOCAL PARENTS SPEAK UP FOR VACCINATION

<City, State> Local parents are teaming up <with local health provider, etc> by hosting a community presentation called <Name of Your Event>. This information session will focus on childhood and adult vaccines. <Event name> will take place at <time> on <date> at <location>.

These moms and dads are members of Voices for Vaccines, a parent led organization that supports and advocates for on time vaccination and the reduction of vaccine preventable disease.

“A vocal opposition to vaccines is compromising immunization rates across the country and causing vaccine preventable diseases to reemerge.” says <parent advocate name,> “The anti-vaccine movement puts our families at risk by spreading misinformation and we want to share the truth about vaccines, and tell other parents why it is important to vaccinate.”

This community presentation is designed to harness the power of peer-to-peer influence while providing scientifically sound information. A <physician, pediatrician, etc> from <office> will also be available to answer questions.

Voices for Vaccines (VFV) is a parent driven organization supported by scientists, doctors, and public health officials that provides parents clear, science based information about vaccines and vaccine preventable disease, as well as an opportunity to join the national discussion about the importance of on time vaccination.

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For more information, or to schedule an interview, contact <name> at <phone number> or <email>

SURVEY

Date: _____ Location: _____

Presenter: _____

Before attending this event, did you have questions or concerns about vaccines that impacted your decision to vaccinate your children?

___ YES ___ NO

How did the information provided in this presentation influence your decision to vaccinate your children?

___ More likely to vaccinate on schedule ___ No Change ___ Less likely to vaccinate on schedule

How did the information provided in this presentation influence your decision to be an advocate for on-schedule vaccination.

___ More likely to be an advocate ___ No Change ___ Less likely to be an advocate

For each question below please circle the number that best represents your thoughts, using the scale of 3 (Agree) to 1 (Disagree)

1 2 3 The presentation was easy to understand

1 2 3 The presenter was knowledgeable

1 2 3 The presentation provided useful information

1 2 3 After hearing this presentation, I feel better equipped to make the decision to vaccinate on schedule

1 2 3 After hearing this presentation, I will be more likely to respond to myths and misinformation about vaccines when I hear them or see them posted online.

What did you like the most about this event?

What did you like least about this event?

Please share your comments on the format of this event.

Please share your comments on the tone of the materials.

What could be improved?

Would you provide us with a quote that we could publicly use as a testimonial for the impact this presentation had on either your decision to vaccinate, your view on vaccination, or your empowerment to be a vaccine advocate? (This will be anonymous).

Thank you!

PUBLICITY RELEASE

I, _____, [being at least eighteen (18) years of age,] [on behalf of a female/male minor named _____] hereby authorize VOICES FOR VACCINES (VFV) to record my [his/her] picture and/or voice photographs, films, tapes, or other media, and [EXCEPT WHERE NOTED BELOW] to use my [his/her] name and biographical information in connection therewith, without further compensation or permission.

I further authorize VFV and/or its agents to record my [his/her] words, voice and likeness, reasonably edit any recordings of my [his/her] words, likeness and/or voice at its reasonable discretion, and to incorporate these recordings into print publications, electronic and online publications, software, movie and sound films or tapes, broadcasts (radio and television), programs, advertising or otherwise, and to use and license others to use such publications, recordings, software, movie and sound films and tapes and broadcast programs and advertisements in any manner of media whatsoever, including unrestricted use for purposes of publicity, advertising and sale promotion, and to use my [his/her] words, name, likeness, voice, and biographic or other information in connection therewith. I understand that VFV exclusively owns all rights to these recordings irrespective of the form in which they are produced or used.

I further agree to indemnify and save harmless VFV, its licensees, agents, successors and assigns from any and all third party claims and liability for damages, losses, or expenses of any sort arising directly from my participation in the recording, including, without limitation, claims with respect to my [his/her] right to privacy or publicity.

I have read and understood the contents hereof, and have the right and authority to execute this release and indemnification. I understand that this Liability/Publicity Release is to be interpreted under the laws of the State of Georgia without resort to its conflict of laws rules, and I hereby submit to the jurisdiction of the courts of the State of Georgia.

EXCEPTIONS OR RESTRICTIONS: _____ None
As Noted:

Date

Signature

Name:
Address:
City/State/Zip:
Tel.: