

Selecting and Evaluating Sources of Patient Education Materials

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Learning Objectives

After reading this chapter, the healthcare provider will be able to do the following:

- Recognize and analyze various patient education materials in terms of types and sources.
- Evaluate patient education materials for bias, language, and cost.
- Provide appropriate sources of patient education to various patient populations.

Main Points

- Patient education draws on a broad-based set of materials that can help explain a spectrum of topics.
- Patient education materials include sources in print, pictures and diagrams, multimedia, and the Internet.
- Patient education materials can easily be procured from pharmaceutical companies, professional and disease-specific organizations, the government, medical journals, the popular press, and food companies.
- Ideally, a clinician should have many different kinds of patient education materials available to accommodate every patient's needs.

Introduction

Patient education draws on a broad-based set of materials that can help explain a spectrum of topics. On some occasions, the patient education process is short and quite focused, while at other times it is long and detailed. An example of a brief encounter is the education of a patient on an acute medical problem, like a viral sore throat, which has few sequelae and will respond without particular treatment. For such a medical problem, usually a brief discussion of palliative treatments (e.g., saline gargles and throat lozenges) is all that is needed. On the other hand, patient education needs to be more detailed for a condition of longer duration, such as pregnancy or a chronic disease state like diabetes. In these two conditions, there

are continual changes that occur and many behaviors to explain. One would need to use several techniques and allow sufficient time to explain both types of problems. This chapter provides an overview of the various patient education materials. Chapters 3 and 6 also provide related information.

Types of Instructional Materials

There are many types of instructional aids that can be used with patients. The first major category is printed material. Fact sheets are usually single-page sheets used to distill information about a disease or treatment. These fact sheets give the major points of information and are useful for the patient to use as guidelines at home. The advantages of fact sheets are that they are short and can easily keep the attention of the patient. The single-page fact sheet can be of low cost to procure or reproduce and can be modified with individual instructions for each patient. Individualization can be accomplished by having an area at the bottom of the sheet for personal instruction or by having the fact sheets on a computer so specifics can be filled in before printing. Single-sheet handouts are easy to keep in a file drawer or folder in the examining room for easy access. For offices with computer capability in the examining rooms, the sheet can be printed at the time of need, obviating the need for storage of preprinted materials.

Disadvantages of fact sheets include that they may be too short to be very detailed and may not answer some of the patient's questions, especially if the disease process or its treatment is very complex. It is possible that fact sheets may be more expensive if reproduced from rented or leased computer software than if they are produced by the clinic personnel. If a computer and printer are required for reproduction of fact sheets, it would add to the cost. If a computer system is already in place, the added cost is minimal when the fact sheets are designed by clinic personnel.

Another type of printed material is pamphlets, which are usually small in size and pertain to a particular disease

or treatment. Advantages of pamphlets are that they are short and may be provided at no cost by pharmaceutical companies or low cost by professional societies. These materials are professionally designed, edited, and printed. Pharmaceutical companies frequently provide patient education pamphlets describing the pathophysiology and treatment of conditions that the drugs they sell are intended to treat. For example, a pharmaceutical company that sells a major antihypertensive drug may provide materials about hypertension and its treatment. These types of pamphlets should be evaluated for bias before they are given to patients.

Disease-specific and professional societies may provide pamphlets about the disease or condition that is their cause. For example, the American Cancer Society provides materials about specific tumors and prevention of cancer. Another type of society is a group of health professionals who have a particular medical interest. The American Academy of Ophthalmology provides information about diseases of the eye in general as well as specific eye disease entities, like macular degeneration and diabetic retinopathy.

Health departments may also provide pamphlets for local use concerning problems in a particular community. These pamphlets may reflect the diversity of the local population and may be in languages other than English. These materials are usually free of cost, but they may not be as professionally produced, may not use glossy paper, and may include no photographs.

One of the disadvantages of pamphlets is that they cannot usually be personalized for a particular patient. Some pamphlets are intended to sell or accompany particular drugs and may give undue emphasis to that drug treatment regimen or pharmaceutical company, while others give balanced views of the options available. It is wise to review all materials for suitability to one's patient population.

Books are another level of printed material and include fuller information about a disease or condition, with consideration given to explicit, detailed discussion of the topics. These books may be provided by the clinician's practice or recommended for the patient to purchase. Some books may be provided free of charge by pharmaceutical companies or at low cost by professional or disease-oriented associations.

One advantage of a book is that more detail is available concerning the disease or condition. The increased level of detail may reduce requests for further information, because the patient can refer to the resource rather than contact the medical care provider. For example, an obstetrician's practice may provide a small paperback about pregnancy and related issues that explains basics of related problems and states measures to be taken, as well as when further input by the healthcare provider is warranted.

Disadvantages of books include high cost because they are usually more expensive than fact sheets or pamphlets. The reading level may also be higher than for the less detailed forms of printed information. Because much more information is presented, there is more opportunity for information to be at variance with the clinician's beliefs.

Books are not as easily updated as shorter forms of printed materials and, of course, are not personalized for a particular practice setting or patient.

Magazines are another form of printed material. Magazines contain articles that usually highlight a new breakthrough in the diagnosis or treatment of a disease or condition, making the topic newsworthy. Magazine articles usually contain up-to-date information and make information widely available to the general public. Magazine articles may not have a medical point of view, which may be a disadvantage. Articles may be of use at or near the time of publication, but they are not updated on a regular basis and therefore may be of limited value as they become less current. A noteworthy article can usually be reproduced with permission of the publisher.

Photonovelas are a new format for patient education akin to a comic book and are especially useful in populations with low literacy. The format uses photos instead of drawings and includes conversation within bubbles as in a comic book. The technique may be developed by using a focus group within the specific population to make the content as culturally appropriate as possible. As the name indicates, the technique has been used with Spanish-speaking populations thus far, but its use could spread to other populations in the future.¹

Some practices keep special anatomic pictures in the examining rooms to help clinicians explain common problems. For example, anatomic ear diagrams are used in many practices where otitis media is a common disorder. As necessary, the clinician can point out the anatomic problem as the condition is being discussed. Some practices have added chalkboards to examining rooms so that spontaneous drawings can be made by the healthcare provider or patient educator. Some clinicians resort to drawings on paper to help describe the problem.

Audiovisual materials do not require patients to have reading ability. Several types of audiovisuals may be used. Although not used very often today, audiotapes are inexpensive. In the future, however, the popularity of this technology may diminish in favor of other audiovisual formats.

DVDs are an option for distributing patient education information. Videos on DVDs about various medical topics are produced and electronically distributed by pharmaceutical companies, hospitals, and office practices. Many patients have DVD players in their homes, which makes this technique very effective. This method is especially helpful for demonstrating skills because the video can be replayed and stopped at the will of the viewer so that skills can be practiced. Some practice settings have DVD players in the waiting room or in a viewing room so that videos can be viewed at the practice setting and questions can be answered after the video is viewed. This method is effective because it takes advantage of more than one route for imparting information. It is also independent of reading level. The cost may be a drawback for some. It is cheapest to lend the DVD to the patient for home viewing, with subsequent return to the practice when finished. A more expensive approach is to set up a

DVD viewing area in the practice setting; however, this requires designated space for viewing, DVD storage, a DVD player, equipment maintenance, and security measures. If a lending library is used, there are personnel costs for keeping track of materials. Other more advanced forms of technology, such as interactive video, computer-assisted instruction, and medical television programs, increase costs even more.

For teaching activities, such as how to give an injection, a video may be quite useful. A video can be used to show the process for initial teaching, and then it can be given to patients to review at home to help them become comfortable with the process. Video may include formats such as DVDs, which requires a DVD player for home use, or an online video, which requires a computer with online access. Other patient education videos may be distributed as podcasts on the Internet and downloaded to an MP3 player. Many patients have these technologies, and even lower socioeconomic populations have the technology with increasing frequency. As for usage by age group for computers, even those older than age 65 years have and use computers. If the use of technology is suggested, the clinician should always ascertain if the patient has the appropriate tools and knowledge to use it.

The Internet is now considered by most to be the easiest location to acquire information. For patient education content it becomes a bit tricky because information is not filtered according to its accuracy. Patients are left to evaluate this on their own or ask their provider for advice. This latter step defeats the purpose of encouraging patients to become more capable of making choices regarding their healthcare options.² As patients learn how to access, research, and evaluate medical information, the traditional information gap between the patient and clinician will likely fade.² However, this will require clinicians to provide patient guidance whenever possible. Utilizing e-mail, dedicated practice Web sites, blogs, chat rooms, and so forth for patient education purposes is relevant here because these are becoming a more common form of interacting with patients. Reimbursement for time interacting with patients in this fashion has become problematic because insurers are reluctant to reimburse clinicians for this type of activity.² To assist one's patient population in this endeavor, there are a few items to present here as summarized in an article from Tufts Managed Care Institute.²

- Information from the Internet, like any other source, complements rather than replaces information provided by a clinician.
- When evaluating the credibility of Web sites, look for the credentials of authors and contributors, relevant copyright information, ownership disclosure, and the date of posting.
- Sites developed by government agencies (e.g., National Library of Medicine [Information Rx], National Institutes of Health), professional and voluntary associations (e.g., American Medical Association, American Cancer Society), leading and respected clinical centers (e.g., Mayo Clinic), universities (e.g., University of Texas MD

Anderson Cancer Center), and certain commercial companies (e.g., Krames On-Demand, the official patient education publisher for the American Health Association, American Lung Association, American Stroke Association, and Harvard Health Publications) are useful places to refer patients.

With the advent of electronic medical records, some systems have associated patient education materials that can be printed for any individual patient problem or concern. The materials are often from proprietary medical patient education databases, such as WebMD, MD Consult, or McKesson. Care should be taken to review the material with the patient and emphasize any vital aspects of care. On occasion the amount of patient information that can be printed from databases can be overwhelming, and important information may be missed by patients trying to wade through numerous pages of information.

Finally, classes and self-help groups offered by health-care workers and other professionals can present information regarding a particular subject (e.g., diabetes and nutrition). These sessions may be presented in a classroom, workshop, or small group. An advantage of this approach is that information can be shared easily, with immediate reinforcement. The cost associated with this format may be prohibitive in some practices and for some patients, but some insurance companies may reimburse this type of medical expense.

Sources of Instructional Material

Patient education materials can be found through many sources. Pharmaceutical and medical equipment companies often provide disease or condition information related to the drugs or other products the company sells. Materials vary greatly, as described earlier. The materials can be procured by contacting the company or its representative. Current addresses and telephone numbers can be found in the *Physicians' Desk Reference*.

Professional organizations can be a source of balanced education materials. The American College of Obstetricians and Gynecologists, American Academy of Dermatology, American Medical Association, and American Academy of Pediatrics are cases in point (Appendix 2–1).

The US government is a source for many low-cost, balanced patient education materials (Appendix 2–2). An advantage of government information sources is that they are not copyrighted and can be used free of charge. Basic information can be procured through its consumer education division in Pueblo, Colorado. Other information can be gained through contacting specific sections of the government that lead research efforts for specific diseases. For example, the National Heart, Lung, and Blood Institute provides information on heart and lung diseases, whereas the National Cancer Institute provides information on cancers. Both have materials related to changing behaviors and prevention.

Some medical journals provide articles that have information specifically designed for patients and can either be duplicated or purchased for distribution. This

information is often written by leading experts in the medical field and reports cutting-edge material and the latest advances in medicine.

The popular press provides many types of patient information. Local newspapers and news magazines (like the *New York Times*, *Time*, *U.S. News and World Report*, and *Newsweek*) and other monthly publications (like *Men's Health* and *Woman's Day*) provide information in health columns and occasionally as cover story material. Other magazines (like *Consumer Reports*) may provide special medical reports in the magazine and then as reprints. Other publishers use magazines to impart information, such as Lamaze and childbirth information.

Food and food product vendors may be the source for a variety of materials related to food issues. Types of information that may be obtained include diet instruction sheets; recipes; low-calorie, low-sodium, or low-cholesterol diets; information on the relationship between diet and disease; and information on feeding infants. Types of products that often have information with them include sugar substitutes, decaffeinated products, low-fat and low-cholesterol foods, dietary supplements, baby food, and infant formula. The information may be displayed with the food or food product and may contain a patient incentive, including coupons and rebates.

Disease-specific foundations and societies are also a good place to find balanced information on a disease or condition (Appendix 2–3). Examples include the American Heart Association, Arthritis Foundation, National Kidney Foundation, American Diabetes Association, and American Cancer Society. Many types of information are available to help patients and their families understand and live with the disease or condition.

Proprietary sources include businesses that sell patient education materials. This may include paper copy as well as Internet access to materials. Companies such as Krames and Channing Bete Company publish information about numerous patient problems and medical procedures. The types of materials range from basic pamphlets, to workbooks about management of common diseases with complex treatments, to videos showing various procedures. The cost of the item is in proportion to its complexity, with pamphlets the cheapest and video the most expensive per unit. Such materials can be personalized with the practice address and contact information for an additional charge. The cost per unit of such materials can be lessened when ordering larger numbers of copies. Proprietary businesses may also have an online system for patient education available on a subscription basis. Such companies take language level, language translation, and cultural sensitivity under advisement when developing the materials. The materials are reviewed for accuracy and updated as information changes.

Factors for Evaluation

It is important to pick the appropriate tool for the job. Ideally, a clinician should have many different kinds of patient education materials available to accommodate

every patient's needs. Because this is prohibitive in most practice settings, each situation should be evaluated and the right amount of information should be presented. Some materials, especially those provided by for-profit businesses, may contain a significant product slant. All materials should be evaluated closely so that the message presented is as close to what the clinician wants to impart as possible. With any printed text, the material may not be presented at the appropriate level of language for the patient and may not be in the patient's primary language. English is the primary language used in most written materials. Occasionally, and now more frequently than in years past, materials in different languages, such as Spanish, are available. The reading level of materials in English can be estimated using the Simple Measure of Gobbledygook (SMOG) readability formula, Fry Graph Readability Formula, or other reading level formula.^{3–5} Some research has been conducted using similar formulas to estimate the reading level of materials written in Spanish. It is suggested that materials be at a basic level of language, grades 4 to 8, so that most patients will be able to comprehend the medical messages. Other languages are available in some circumstances and locations. Some health-oriented Web sites are available in numerous languages with graphics appropriate to the culture of the language. One such Web site is networkofstrength.org, a Web site sponsored by the Breast Cancer Network of Strength (formerly Y-ME National Breast Cancer Organization). The Web site has breast cancer screening, treatment, and emotional support information in seven languages, including Spanish, Russian, Chinese, Vietnamese, Tagalog, and Korean in addition to English. As time passes, more medical information Web sites will follow this trend. When it is necessary to have materials in different languages, practice-generated materials should be translated by a professional so that information is accurately relayed. The use of online translating programs without contextual review by a translation professional should be avoided. The cost of any patient education method needs to be determined and fit into the practice budget.

According to Pfizer Health Literacy and other sources, items to consider for review are numerous.⁴ The layout should be plain and not detract attention from the messages to be imparted. Language should be in the active voice, and action verbs should be used. A font size of 12 point should be used. There should be attention to having white areas on the page or screen so that it looks easy to read. The reading level should be calculated for appropriateness. Check for the use of bold fonts and italic for adding emphasis, and avoid underlining. Look for the use of technical terms or jargon that could confuse the reader. Address the use of graphics to ensure they are appropriate for the intended population, and evaluate the contrast between the type and the background for sharpness. Information should be accurate and objective, and it should be organized in a logical format. The point of view should be reviewed to reveal any bias.

Conclusion

Patient education materials are an important part of the patient education process. Finding materials appropriate for a specific practice setting can help make the job of the clinician easier by replicating the specific message desired to be imparted. The materials are only one part of the process of performing patient education, but they are an important one because they will represent the message long after the clinician and patient are through with their visit.

References

1. Cornett S. Assessing and addressing health literacy. *Online J Issues Nurs.* 2009;14(3). <http://www.nursingworld.org/MainMenuCategories/ANAMarketplace/ANAPeriodicals/OJIN/TableofContents/V01142009/N03Sept09/Assessing-Health-Literacy-.aspx#Pfizer07>. Accessed April 5, 2010.
2. Tufts Managed Care Institute. Patient education and the Internet. <http://www.thci.org/downloads/ttopic91001.pdf>. Accessed March 31, 2010.
3. McLaughlin GH. SMOG grading: a new readability formula. *J Read.* 1969; 12(8):639–646.
4. Pfizer Public Health Group. Fry testing. <http://www.pfizerhealthliteracy.com/physicians-providers/fry-testing.html>. Accessed April 5, 2010.
5. Doak LG, Doak CC. Pfizer principles for clear health communication: a handbook for creating patient education materials that enhance understanding, promote health outcomes. <http://www.pfizerhealthliteracy.com/pdf/Pfizer-Principles.pdf>. Accessed April 5, 2010.

List of Professional Organizations

American Academy of Allergy, Asthma & Immunology

555 E. Wells St., Ste. 1100
Milwaukee, WI 53202
Phone: 414-272-6071
<http://www.aaaai.org/>

American Academy of Dermatology

930 E. Woodfield Rd.
Schaumburg, IL 60173
Correspondence Address:
PO Box 4014
Schaumburg, IL 60168
Phone: 847-330-0230
Toll free: 1-866-503-7546
Fax: 847-240-1859
<http://www.aad.org/index.html>

American Academy of Family Physicians

11400 Tomahawk Creek Pkwy.
Leawood, KS 66211-2680
Phone: 913-906-6000
Toll free: 1-800-274-2237
Fax: 913-906-6075
<http://www.aafp.org>

American Academy of Home Care Physicians

PO Box 1037
Edgewood, MD 21040-0337
Phone: 410-676-7966
Fax: 410-676-7980
<http://www.aahcp.org>

American Academy of Neurology

1080 Montreal Ave.
St. Paul, MN 55116
Phone: 651-695-2717
Toll free: 1-800-879-1960
Fax: 651-695-2791
E-mail: memberservices@aan.com
<http://www.aan.com>

American Academy of Orthopaedic Surgeons

6300 N. River Rd.
Rosemont, IL 60018-4262
Phone: 847-823-7186
Toll free: 1-800-346-2267
Fax: 847-823-8125
<http://www.aaos.org>

American Academy of Pediatrics

141 Northwest Point Blvd.
Elk Grove Village, IL 60007
Phone: 847-434-4000
Fax: 847-434-8000
<http://www.aap.org>

American Burn Association

625 N. Michigan Ave., Ste. 2550
Chicago, IL 60611
Phone: 312-642-9260
Fax: 312-642-9130
E-mail: info@ameriburn.org
<http://ameriburn.org>

American College of Emergency Physicians

PO Box 619911
Dallas, TX 75261-9911
Phone: 972-550-0911
Toll free: 1-800-798-1822
<http://www.acep.org>

American College of Gastroenterology

PO Box 342260
Bethesda, MD 20827-2260
Phone: 301-263-9000
<http://www.acg.gi.org>

American College of Physicians

190 N. Independence Mall W.
Philadelphia, PA 19106-1572
Phone: 215-351-2400
Toll free: 1-800-523-1546
<http://www.acponline.org>

American College of Radiology
1891 Preston White Dr.
Reston, VA 20191
Phone: 703-648-8900
<http://www.acr.org>

American College of Surgeons
633 N. St. Clair
Chicago, IL 60611
Phone: 312-202-5000
<http://www.acsbscn.org>

**American Congress of Obstetricians
and Gynecologists**
409 12th St. SW
Washington, DC 20024-2188
Correspondence Address:
PO Box 96920
Washington, DC 20090-6920
Phone: 202-638-5577
<http://www.acog.org>

American Diabetes Association
Attn: National Call Center
1701 N. Beauregard St.
Alexandria, VA 22311
Toll free: 1-800-342-2383
<http://www.diabetes.org>

American Gastroenterological Association
4930 Del Ray Ave.
Bethesda, MD 20814
Phone: 301-654-2055
Fax: 301-654-5920
<http://www.gastro.org>

American Geriatrics Society
Empire State Building
350 Fifth Ave., Ste. 801
New York, NY 10118
Phone: 212-308-1414
Fax: 212-832-8646
E-mail: info@americangeriatrics.org
<http://www.americangeriatrics.org>

American Hospital Association
One N. Franklin
Chicago, IL 60606-3421
Phone: 312-422-3000
<http://www.aha.org>

American Medical Association
515 N. State St.
Chicago, IL 60610
Toll free: 1-800-621-8335
<http://www.ama-assn.org>

American Neurological Association
5841 Cedar Lake Rd., Ste. 204
Minneapolis, MN 55416
Phone: 952-545-6284
Fax: 952-545-6073
E-mail: ana@llmsi.com
<http://www.aneuroa.org>

American Orthopaedic Association
6300 N. River Road, Ste. 505
Rosemont, IL 60018
Phone: 847-318-7330
Phone: 847-318-7339
E-mail: info@aoassn.org
<http://www.aoassn.org>

American Psychiatric Association
1000 Wilson Blvd., Ste. 1825
Arlington, VA 22209-3901
Phone: 703-907-7300
Fax: 703-907-1085
E-mail: apa@psych.org
<http://psych.org>

American Public Health Association
800 I St.
Washington, DC 20001-3710
Phone: 202-777-2574
Fax: 202-777-2534
<http://www.apha.org>

American Society on Aging
71 Stevenson St., Ste. 1450
San Francisco, CA 94105-2938
Phone: 415-974-9600
Toll free: 1-800-537-9728
Fax: 415-974-0300
<http://www.asaging.org>

American Thoracic Society
61 Broadway
New York, NY 10006-2755
Phone: 212-315-8600
Fax: 212-315-6498
<http://www.thoracic.org>

American Urological Association
1000 Corporate Blvd.
Linthicum, MD 21090
Phone: 410-689-3700
Toll free: 1-866-RING-AUA (1-866-746-4282)
Fax: 410-689-3800
<http://www.auanet.org>

Association of Reproductive Health Professionals
1901 L St. NW, Ste. 300
Washington, DC 20036
Phone: 202-466-3825
E-mail: ARHP@arhp.org
<http://www.arhp.org>

Asthma and Allergy Foundation of America
1233 20th St. NW
Washington, DC 20036
Phone: 202-974-1220
<http://www.aafa.org>

Gerontological Society of America
1220 L St. NW, Ste. 901
Washington, DC 20005
Phone: 202-842-1275
Fax: 202-842-1150
<http://www.geron.org>

Infectious Diseases Society of America
1300 Wilson Blvd., Ste. 300
Arlington, VA 22209
Phone: 703-299-0200
Fax: 703-299-0204
E-mail: info@idsociety.org
<http://www.idsociety.org>

National Hospice and Palliative Care Organization
1731 King St., Ste. 100
Alexandria, VA 22314
Phone: 703-837-1500
Fax: 703-837-1233
<http://nhpco.org>

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Federal Agency Contact Information

Centers for Disease Control and Prevention

Toll free: 1-800-232-4636

E-mail: cdcinfo@cdc.gov<http://www.cdc.gov>**Centers for Medicare & Medicaid Services**

Phone: 410-786-3000

<http://www.cms.gov>**Health Resources and Services Administration**

Phone: 301-443-2216

<http://www.hrsa.gov>**Indian Health Service**

Phone: 301-443-1083

<http://www.ihs.gov>**Information Rx (from the National Library of Medicine)**<http://www.informationrx.org/>**Institute of Medicine**

Phone: 202-334-2352

<http://www.iom.edu/>**National Academy of Sciences**

Phone: 202-334-2000

<http://www.nasonline.org>**National Institutes of Health***Clinical Center:*

Phone: 301-496-2563

Fax: 301-402-2984

Division of Computer Research and Technology:

Phone: 301-496-3583

Fogarty International Center for Advanced Study in the Health Sciences:

Phone: 301-496-1415

National Cancer Institute:

Toll free: 1-800-422-6237

<http://www.cancer.gov>*National Center for Research Resources:*

Phone: 301-435-0888

Fax: 301-480-3558

E-mail: info@ncrr.nih.gov<http://www.ncrr.nih.gov>*National Eye Institute:*

Phone: 301-496-5248

www.nei.nih.gov*National Heart, Lung, and Blood Institute:*

Phone: 301-592-8573

Fax: 240-629-3246

E-mail: nhlbiinfo@nhlbi.nih.gov<http://www.nhlbi.nih.gov>*National Institute of Allergy and Infectious Diseases:*

Phone: 301-496-5717

Toll free: 1-866-284-4107

Fax: 301-402-3573

<http://www3.niaid.nih.gov>*National Institute of Arthritis and Musculoskeletal and Skin Diseases:*

Phone: 301-495-4484

Toll free: 1-877-226-4267

Fax: 301-718-6366

E-mail: NIAMSinfo@mail.nih.gov<http://www.niams.nih.gov>*National Institute of Child Health & Human Development:*

Toll free: 1-800-370-2943

Fax: 1-866-760-5947

<http://www.nichd.nih.gov>

National Institute of Dental and Craniofacial Research:
Phone: 301-496-4261
<http://www.nidcr.nih.gov>

*National Institute of Diabetes and Digestive
and Kidney Diseases:*
Phone: 301-496-3583
<http://www2.niddk.nih.gov>

National Institute of Environmental Health Sciences:
Phone: 919-541-3345
Fax: 919-541-4395
<http://www.niehs.nih.gov>

National Institute of General Medical Sciences:
Phone: 301-496-7301
E-mail: info@nigms.nih.gov
<http://www.nigms.nih.gov>

National Institute of Mental Health:
Phone: 301-443-4513
Toll free: 1-866-615-6464
Fax: 301-443-4279
E-mail: nimhinfo@nih.gov
<http://www.nimh.nih.gov>

National Institute of Neurological Disorders and Stroke:
Phone: 301-496-5751
Toll free: 1-800-352-9424
<http://www.ninds.nih.gov>

National Institute of Nursing Research:
Phone: 301-496-0207
Toll free: 1-866-910-3804
TTY: 301-594-5605
Fax: 301-480-8845
<http://www.ninr.nih.gov>

National Institute on Aging:
Phone: 301-496-1752
Fax: 301-496-1072
<http://www.nia.nih.gov>

National Institute on Alcohol Abuse and Alcoholism:
Phone: 301-443-3860
<http://www.niaaa.nih.gov>

*National Institute on Deafness and
Other Communication Disorders:*
Phone: 301-496-7243
Fax: 301-402-0018
E-mail: wengerj@nidcd.nih.gov
<http://www.nidcd.nih.gov>

National Institute on Drug Abuse:
Phone: 301-443-1124
E-mail: information@nida.nih.gov
<http://www.nida.nih.gov>

*US National Library of Medicine
(including Information Rx):*
Phone: 301-594-5983
Toll free: 1-888-346-3656
Fax: 301-402-1384
E-mail: custserv@nlm.nih.gov
www.nlm.nih.gov
<http://www.informationrx.org/>

National Science Foundation
Phone: 703-292-5111
Toll free: 1-800-877-8339
E-mail: info@nsf.gov
<http://www.nsf.gov>

US Department of Health and Human Services
Toll free: 1-877-696-6775
<http://www.hhs.gov>

Adopt a Special Kid:
Phone: 510-553-1748
Toll free: 1-888-680-7349
Fax: 510-553-1747
<http://www.aask.org>

AIDS Hotline, National:
Toll free: 1-800-232-4636
E-mail: cdcinfo@cdc.gov
<http://www.cdc.gov/hiv>

AIDS Information Clearinghouse, National:
Toll free: 1-800-458-5231
<http://www.cdc.gov/hiv>

AIDSinfo:
Toll free: 1-800-TRIALS-A
<http://www.aidsinfo.nih.gov>

National Center for Vision and Aging:
Toll free: 1-800-829-0500

National Institute on Aging:
Phone: 301-496-1752
Fax: 301-496-1072
<http://www.nia.nih.gov>

*Substance Abuse and Mental Health Services
Administration:*
Toll free: 1-800-729-6686
<http://ncadi.samhsa.gov>

US Public Health Service Commissioned Corps:
Phone: 800-279-1605
<http://www.usphs.gov/>

US Food and Drug Administration (FDA)
Toll free: 1-888-463-6332 (main number)
<http://www.fda.gov>
Phone: 301-575-0156

Breast Implant Inquiries:
Phone: 301-594-0485

Center for Biologics Evaluation and Research (CBER):
Phone: 301-827-0372

Center for Devices and Radiological Health:
Phone: 301-796-7100

Center for Drug Evaluation and Research:
Phone: 301-796-5400

Freedom of Information:
Phone: 301-827-4565

General Consumer Inquiries:
Toll free: 1-888-463-6332

Mandatory Medical Device Reporting:
Phone: 301-796-6670

Medical Advertising:
Phone: 301-796-1200
Fax: 301-847-8444

MedWatch (24-hour service for reporting problems with drugs, devices, biologics [except vaccines], medical foods, and dietary supplements):
Toll free: 1-800-332-1088

Office of Orphan Products Development (information on products for rare diseases):
Phone: 301-827-3670

Office of Public Affairs (interviews and press inquiries on FDA activities):
Phone: 301-827-3434

Office of Special Health Issues [Liaison between the Food and Drug Administration (FDA) and patients, patient advocates, and health professional organizations]
Phone: 888-463-6332

Registration of Food Facilities Help Desk:
Toll free: 1-800-216-7331

Seafood Hot Line (24-hour service, prerecorded message for information requests [English and Spanish]):
Toll free: 1-888-723-3366

USP Medication Errors (reporting of medication errors or near errors to help avoid future problems through improvement on product names and packaging):
Toll free: 1-800-332-1088
Fax: 1-800-FDA-0178

Vaccine Adverse Event Reporting (24-hour service):
Toll free: 1-800-822-7967

Veterinary Adverse Drug Reaction Program:
Phone: 240-276-9000
Toll free: 1-888-332-8387

White House
Phone: 202-456-1414

National Health Organizations

800 Cocaine

Toll free: 1-800-262-2463

<http://800cocaine.com>**Academy of Orton-Gillingham Practitioners and Educators (formerly Orton Dyslexia Society)**

Phone: 845-373-8919

Toll free: 1-800-222-3123

Fax: 845-373-8925

E-mail: ortonacademy@verizon.net<http://www.ortonacademy.org>**Al-Anon Family Group Headquarters Inc.**

Phone: 757-563-1600

Fax: 757-563-1655

<http://www.al-anon.org>**ALS Association**

Toll free: 1-800-782-4747

<http://www.alsa.org>**Alzheimer's Association**

Toll free: 1-800-272-3900

<http://www.alz.org>**Alzheimer's Disease Education and Referral Center**

Toll free: 1-800-438-4380

<http://www.nia.nih.gov/alzheimers>**AMC Cancer Fund**

Phone: 303-233-6501

Toll free: 1-800-525-3777

E-mail: contactus@amc.org<http://www.amc.org>**American Association of Kidney Patients**

Toll free: 1-800-749-2257

Fax: 813-636-8122

E-mail: info@aakp.org<http://www.aakp.org>**American Burn Association**

Phone: 312-642-9260

Fax: 312-642-9130

E-mail: info@ameriburn.org<http://www.ameriburn.org>**American Cancer Society**

Toll free: 1-800-ACS-2345

<http://www.cancer.org>**American Childhood Cancer Organization**

Toll free: 1-800-366-2223

Fax: 301-962-3521

E-mail: staff@candlelighters.org<http://www.candlelighters.org>**American Council of the Blind**

Toll free: 1-800-424-8666

<http://www.acb.org>**American Council on Alcoholism and Treatment**

Toll free: 1-800-527-5344

E-mail: info@aca-usa.org<http://www.aca-usa.org>**American Diabetes Association**

Toll free: 1-800-342-2383

<http://www.diabetes.org>**American Foundation for the Blind**

Phone: 212-502-7600

Toll free: 1-800-232-5463

Fax: 1-888-545-8331

E-mail: afbinfo@afb.net<http://www.afb.org>**American Heart Association**

Toll free: 1-800-242-8721

<http://www.americanheart.org>

American Institute for Cancer Research
Toll free: 1-800-843-8114
Fax: 202-328-7226
E-mail: aicrweb@aicr.org
<http://www.aicr.org>

American Kidney Fund
Toll free: 1-800-638-8299
E-mail: helpline@kidneyfund.org
<http://www.kidneyfund.org>

American Liver Foundation
Phone: 212-668-1000
Toll free: 1-800-223-0179
Fax: 212-483-8179
<http://www.liverfoundation.org>

American Lung Association
Phone: 202-785-3355
Toll free: 1-800-LUNG-USA
Fax: 202-452-1805
E-mail: info@lungusa.org
<http://www.lungusa.org>

American Parkinson Disease Association
Phone: 718-981-8001
Toll free: 1-800-223-APDA
Fax: 718-981-4399
E-Mail: apda@apdaparkinson.org
<http://www.apdaparkinson.org>

**American Social Health Association
(formerly National STD Hot Line)**
Phone: 919-361-8400
Toll free: 1-800-227-8922
Fax: 919-361-8425
<https://www.ashastd.org>

American Speech–Language–Hearing Association
Toll free: 1-800-638-TALK
Fax: 301-296-8580
E-mail: actioncenter@asha.org
<http://www.asha.org>

**American Stroke Association (a division
of the American Heart Association;
formerly Stroke Connection)**
Toll free: 1-800-553-6321
Toll free: 1-888-478-7653
<http://www.strokeassociation.org>

Arthritis Consulting Services
Phone: 954-739-3202
Toll free: 1-800-327-3027
Fax: 954-671-1282
<http://www.stoparthritis.com>

Arthritis Foundation
Toll free: 1-800-283-7800
<http://www.arthritis.org>

Asthma and Allergy Foundation of America
Toll free: 1-800-7-ASTHMA
E-mail: info@aafa.org
<http://www.aafa.org>

Back Pain Hotline
Toll free: 1-800-247-2225
<http://www.backpain-hotline.com>

Better Hearing Institute
Phone: 202-449-1100
Toll free: 1-800-327-9355
Fax: 202-216-9646
E-mail: mail@betterhearing.org
<http://www.betterhearing.org>

Blind Childrens Center
Phone: 323-664-2153
Fax: 323-665-3828
<http://www.blindchildrenscenter.org>

Blinded Veterans Association
Phone: 202-371-8880
Toll free: 1-800-669-7079
Fax: 202-371-8258
E-mail: bva@bva.org
<http://www.bva.org>

**Brain Injury Association of America (formerly National
Head Injury Foundation)**
Phone: 703-761-0750
Toll free: 1-800-444-NHIF
Fax: 703-761-0755
<http://www.biausa.org>

**Center for Assistive Technology and Environmental
Access (formerly Center for Rehabilitation
Technology)**
Phone: 404-894-4960
Toll free: 1-800-726-9119
Fax: 404-894-9320
E-mail: catea@coa.gatech.edu
<http://www.catea.gatech.edu>

**Children's Craniofacial Association (formerly
Children's Craniofacial International Foundation)**
Phone: 214-570-9099
Toll free: 1-800-535-3643
Fax: 214-570-8811
E-mail: contactCCA@ccakids.com
<http://www.ccakids.com>

Children's Hospice International
Toll free: 1-800-242-4453
E-mail: info@chionline.org
<http://www.chionline.org>

Children's Tumor Foundation
(formerly Neurofibromatosis Foundation)
Phone: 212-344-6633
Toll free: 1-800-323-7938
Fax: 212-747-0004
E-mail: info@ctf.org
<http://www.ctf.org>

Christopher & Dana Reeve Foundation
(formerly American Paralysis Association)
Toll free: 1-800-225-0292
<http://www.christopherreeve.org>

Cleft Palate Foundation
Phone: 919-933-9044
Toll free: 1-800-242-5338
Fax: 919-933-9604
<http://www.cleftline.org>

Cooley's Anemia Foundation Inc.
Toll free: 1-800-522-7222
Fax: 212-279-5999
E-mail: info@cooleysanemia.org
<http://www.thalassemia.org>

Cornelia de Lange Syndrome Foundation
Phone: 860-676-8166
Toll free: 1-800-753-2357
Fax: 860-676-8337
E-mail: info@cdlsusa.org
<http://www.cdlsusa.org>

Crohn's and Colitis Foundation of America (formerly National Foundation for Ileitis and Colitis)
Toll free: 1-800-343-3637
E-mail: info@ccfa.org
<http://www.ccfa.org>

Cystic Fibrosis Foundation
Phone: 301-951-4422
Toll free: 1-800-FIGHT-CF
Fax: 301-951-6378
<http://www.cff.org>

Deaf Education (Educational Enhancement for the Field of Deaf Education)
Phone: 803-576-9303
Toll free: 1-800-237-6213
TTY: 803-576-9175
Fax: 803-576-9228
<http://www.deafed.net>

Deafness Research Foundation
Toll free: 1-800-535-3323
<http://www.drf.org>

Depression and Bipolar Support Alliance
(formerly National Depressive and Manic Depressive Association)
Toll free: 1-800-826-3632
Fax: 312-642-7243
<http://www.dbsalliance.org>

Ear Foundation
Phone: 615-329-7809
Toll free: 1-800-545-4327
Fax: 615-329-7935
www.earfoundation.org

Easter Seals
Phone: 312-726-6200
Toll free: 1-800-221-6827
Fax: 312-726-1494
<http://www.easterseals.com>

Endometriosis Association
Phone: 414-355-2200
Toll free: 1-800-992-3636
Fax: 414-355-6065
<http://www.endometriosisassn.org>

Epilepsy Foundation of America
Toll free: 1-800-332-1000
E-mail: info@efa.org
<https://www.epilepsyfoundation.org>

Epilepsy Network (formerly Epilepsy Information Service)
Phone: 831-475-9110
Toll free: 1-800-642-0500
E-mail: info@epilepsynetwork.org
<http://www.epilepsynetwork.org>

EyeCare America (formerly National Eye Care Project)
Phone: 877-887-6327
Toll free: 1-800-222-3937
Fax: 415-561-8567
<http://www.eyecareamerica.org>

First Candle
Toll free: 1-800-221-SIDS
E-mail: info@firstcandle.org
<http://www.firstcandle.org>

Foundation Fighting Blindness (formerly National Retinitis Pigmentosa Foundation)
Phone: 410-568-0150
Toll free: 1-800-683-5555
E-mail: info@FightBlindness.org
<https://www.blindness.org>

Guide Dog Foundation for the Blind

Phone: 631-930-9000
Toll free: 1-800-548-4337
Fax: 631-930-9009
<http://www.guidedog.org>

Healthy Mothers, Healthy Babies Coalition

Phone: 703-837-4792
Fax: 703-684-5968
E-mail: info@hmhb.org
<http://www.hmhb.org>

Hearing Information Center

Toll free: 1-800-622-3277

Huntington's Disease Society of America

Phone: 212-242-1968
Toll free: 1-800-345-HDSA
Fax: 212-239-3430
E-mail: hdsainfo@hdsa.org
<http://www.hdsa.org>

Impotence Information Center

Toll free: 1-800-843-4315
Fax: 952-930-6373

International Foundation for Research and Education on Depression (iFred)

Toll free: 1-800-442-4673
<http://www.ifred.org>

International Hearing Society

Phone: 734-522-7200
Toll free: 1-800-521-5247
Fax: 734-522-0200
<http://ihsinfo.org>

Juvenile Diabetes Research Foundation International

Toll free: 1-800-533-CURE (2873)
Fax: 212-785-9595
E-mail: info@jdrf.org
<http://www.jdrf.org>

Kansas Department on Aging

Toll free: 1-800-621-0379
<http://www.agingkansas.org>

Lighthouse International (formerly National Center for Vision and Aging)

Phone: 212-821-9200
Toll free: 1-800-334-5497
Toll free: 1-800-829-0500
Fax: 212-821-9707
E-mail: info@lighthouse.org
<http://www.lighthouse.org>

Lung Line (National Jewish Health)

Toll free: 1-800-222-LUNG
E-mail: lungline@njhealth.org
<http://www.nationaljewish.org/about/contact/lung-line.aspx>

Lupus Foundation of America

Phone: 202-349-1155
Toll free: 1-800-558-0121
Fax: 202-349-1156
<http://www.lupus.org>

Mental Health America (formerly National Mental Health Association)

Toll free: 1-800-969-6642
<http://www.mhacv.org> (Central Virginia)
<http://www.mhala.org> (Los Angeles, California)

Myasthenia Gravis Foundation of America Inc.

Phone: 212-297-2156
Toll free: 1-800-541-5454
Fax: 212-370-9047
<http://www.myasthenia.org>

National Alliance on Mental Illness

Phone: 703-524-7600
Toll free: 1-800-950-NAMI
Member Services: 1-888-999-NAMI (6264)
Fax: 703-524-9094
<http://www.nami.org>

National Autism Hotline

Phone: 304-525-8014
Fax: 304-525-8026

National Center for Stuttering

Toll free: 1-800-221-2483
<http://www.stuttering.com>

National Council on Alcohol and Drug Dependence Inc.

Phone: 212-269-7797
Toll free: 1-800-NCA-CALL
Fax: 212-269-7510
E-mail: national@ncadd.org
<http://www.ncadd.org>

National Council on Child Abuse and Family Violence

Phone: 202-429-6695
Fax: 202-521-3479
E-mail: info@nccafv.org
<http://www.nccafv.org>

National Down Syndrome Congress

Phone: 770-604-9500
Toll free: 1-800-232-NDSC
Fax: 770-604-9898
E-mail: info@ndsccenter.org
<http://www.ndsccenter.org>

National Down Syndrome Society

Toll free: 1-800-221-4602
E-mail: info@ndss.org
<http://www.ndss.org>

**National Drug Information Treatment
and Referral Hotline (formerly National Drug
Information and Referral Line)**

Toll free: 1-800-662-HELP

National Epilepsy Library

Toll free: 1-800-EFA-4050
Fax: 301-459-3700
E-mail: efanel@capcon.net
<https://www.epilepsyfoundation.org>

National Foundation for Facial Reconstruction

Phone: 212-263-6656
Fax: 212-263-7534
<http://www.nffr.org>

National Federation of the Blind

Toll free: 1-800-638-7518
<http://www.nfb.org>

National Headache Foundation

Phone: 312-274-2650
Toll free: 1-888-643-5552
E-mail: info@headaches.org
<http://www.headaches.org>

National Hemophilia Foundation

Phone: 212-328-3700
Toll free: 1-800-42-HANDI
Fax: 212-328-3777
E-mail: handi@hemophilia.org
<http://www.hemophilia.org>

National Hospice and Palliative Care Organization

Phone: 703-837-1500
Toll free: 1-800-658-8898
Fax: 703-837-1233
E-mail: nhpco_info@nhpco.org
<http://www.nhpco.org>

**National Information Clearinghouse Infants
With Disabilities and Life-Threatening Conditions**

Toll free: 1-800-922-9234

National Kidney Foundation

Phone: 212-889-2210
Toll free: 1-800-622-9010
Fax: 212-689-9261
<http://www.kidney.org>

National Lymphedema Network

Phone: 415-908-3681
Toll free: 1-800-541-3259
Fax: 415-908-3813
E-mail: nlm@lymphnet.org
<http://www.lymphnet.org>

National Multiple Sclerosis Society

Toll free: 1-800-344-4867
<http://www.nationalmssociety.org>

National Organization for Rare Disorders

Phone: 203-744-0100
Toll free: 1-800-999-6673
Fax: 203-798-2291
E-mail: RN@rarediseases.org
<http://rarediseases.org>

National Osteoporosis Foundation

Phone: 202-223-2226
Toll free: 1-800-223-9994
Toll free: 1-800-231-4222
<http://www.nof.org>

National Parkinson Foundation

Phone: 305-243-6666
Toll free: 1-800-327-4545
Fax: 305-243-6073
E-mail: contact@parkinson.org
<http://www.parkinson.org>

National Rehabilitation Information Center

Phone: 301-459-5900
Toll free: 1-800-346-2742
E-mail: naricinfo@heitechservices.com
<http://www.naric.com>

National Reye's Syndrome Foundation

Toll free: 1-800-233-7393
E-mail: nrsf@reyessyndrome.org
<http://www.reyessyndrome.org>

National Spinal Cord Injury Association

Toll free: 1-800-962-9629
E-mail: info@spinalcord.org
<http://www.spinalcord.org>

National Stroke Association

Toll free: 1-800-787-6537
<http://www.stroke.org>

Prevent Blindness America

Toll free: 1-800-331-2020

E-mail: HParry@PreventBlindness.org<http://www.preventblindness.org/>**Recording for the Blind and Dyslexic**

Toll free: 1-800-221-4792

<http://www.rfbd.org>**Scleroderma Foundation**

Phone: 978-463-5843

Toll free: 1-800-722-4673

Fax: 978-463-5809

<http://www.scleroderma.org>**Sickle Cell Disease Association of America Inc.**

(formerly National Association for Sickle Cell Disease)

Phone: 410-528-1555

Toll free: 1-800-421-8453

Fax: 410-528-1495

E-mail: scdaa@sicklecelldisease.org<http://www.sicklecelldisease.org>**Simon Foundation for Continence**

Phone: 847-864-3913

Toll free: 1-800-23-SIMON

Fax: 847-864-9758

<http://www.simonfoundation.org>**Spina Bifida Association**

Phone: 202-944-3285

Toll free: 1-800-621-3141

E-mail: sbaa@sbaa.org<http://www.spinabifidaassociation.org>**The Living Bank**

Toll free: 1-800-528-2971

Fax: 713-961-0979

E-mail: info@livingbank.org<http://www.livingbank.org>**Tourette Syndrome Association**

Phone: 718-224-2999

Phone: 718-279-956

Toll free: 1-800-237-0717

<http://www.tsa-usa.org>**Tuberous Sclerosis Alliance**

Phone: 301-562-9890

Toll free: 1-800-225-NTSA

Fax: 301-562-9870

E-mail: info@tsalliance.org<http://www.ntsaa.org>**United Leukodystrophy Foundation**

Toll free: 1-800-728-5483

Fax: 815-895-2432

E-mail: office@ulf.org<http://www.ulf.org>**United Ostomy Associations of America**

Toll free: 1-800-826-0826

<http://www.uoaa.org>**Visiting Nurse Associations of America**

Phone: 202-384-1420

Toll free: 1-800-426-2547

Fax: 202-384-1444

E-mail: vnaa@vnaa.org<http://vnaa.org>