

# Genetic Alliance: Access to Information

Natasha Bonhomme

# Need for Credible Information

- Decide what kind of information families and healthcare providers need to make informed decisions about taking care of a person who has a rare disorder.
- Develop ways to decide if information on a rare disorder is accurate.
- Create new ways to help people develop accurate information about rare disorders.

# ATCGRN

- A CDC funded grant
- \$4 million budget
- Purpose: to examine evidence based information
- Result: Toolbox for consumers to access information
  - Quality Assessment Toolbox



# Disease InfoSearch

- Information about 6000+ rare conditions
- Maintained by the true experts: disease specific advocacy organizations

Genetic Alliance - Disease InfoSearch

http://www.geneticalliance.org/ws\_display.asp?filter=diseases

Genetic Alliance

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## Tools

**Disease InfoSearch**  
What is a Genetic Disease?  
Disease InfoSearch Inclusion Guidelines

Resource Repository  
Guide to Understanding Genetics  
Family Health History  
ATCG

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**Disease InfoSearch**

Select Alphabetical  
# A B C D E F G H I J K L  
M N O P Q R S T U V W X  
Y Z

What's this?

**Organization Search**

Select Alphabetical  
# A B C D E F G H I J K L  
M N O P Q R S T U V W X  
Y Z

## Genetic Alliance Disease InfoSearch

Online database of advocacy organizations and resources for genetic conditions

**Disease InfoSearch Inclusion Guidelines**

Disease InfoSearch, an online search tool and database, is a compilation of information on genetic conditions provided and vetted by disease-specific advocacy organizations. Disease InfoSearch provides up-to-date information and quality links on:

- support groups
- clinical descriptions
- treatments
- research
- insurance issues
- arts and literature

Quality information about genetic conditions should be readily available to individuals and families affected by genetic conditions. Condition-specific advocacy organizations are the premier providers of this information. These organizations provide the tools needed to cope day to day, find solutions, obtain services, and heal. They know first-hand what it means to be faced with a diagnosis and the subsequent need for accurate information. As experts in their condition, advocacy groups are highly motivated to keep this information up-to-date and accessible and to share it with the community.





**Disease InfoSearch**

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Select **Alphabetical**

# A B C D E F G H I J K L  
M N O P Q R S T U V W X  
Y Z

What's this?

**Organization Search**

Select **Alphabetical**

# A B C D E F G H I J K L  
M N O P Q R S T U V W X  
Y Z

What's this?

**Resource Repository**

**Go**

>> Advanced Search

What's this?

## Disease InfoSearch Results

22 Results found for: **Duchenne Muscular Dystrophy**

Links provided by disease-specific organizations.

EXPAND ALL | CLOSE ALL

- ▶ **Support Groups** (3 results)
- ▶ **Clinical Description** (6 results)
- ▶ **Treatment** (3 results)
- ▶ **Research** (4 results)
- ▶ **General Information** (6 results)

See National Library of Medicine Resources for **Duchenne Muscular Dystrophy** **GO**



## Resources for Duchenne Muscular Dystrophy

### Just Diagnosed?

These links offer good starting points to begin learning about Duchenne Muscular Dystrophy.

- ▶ [Duchenne Muscular Dystrophy: The Basics](#)
- ▶ [Gene Testing, Doctors, and Clinical Trials](#)
- ▶ [Understanding Genetics](#)

### Your Reference Library

After learning the basics of Duchenne Muscular Dystrophy, look here for more detailed information.

New scientific findings can rapidly change medical understanding of the condition. The Duchenne Muscular Dystrophy support group may help identify the most accurate information about Duchenne Muscular Dystrophy.

- ▶ [NCBI Bookshelf \(92\)](#)
- ▶ [Medical Dictionary and Encyclopedia](#)
- ▶ [Duchenne Muscular Dystrophy Advanced Reference Material](#)

### How To Use This Site

This site pulls together the latest research and explanatory materials about Duchenne Muscular Dystrophy from NCBI's databases and other sources.

- [What can I find here?](#)
- [Who is this page for?](#)
- [Who is NCBI?](#)
- [Who is Genetic Alliance?](#)

### Search NCBI for Duchenne Muscular Dystrophy

Choose a NCBI database and enter a subject below:

Search in

for

Search for **Duchenne Muscular Dystrophy** in all of NCBI's databases. You will see the number of records in each database that match the disorder and can then go to any of the databases.



Site Search

Browse by Topic

Select a File Type

- Documents
- Video Files
- Audio Files

Choose a Source

- Resource Repository
- Genetic Alliance
- Genetic Wiki
- Genetic Alliance Forum

**RSS** [what's this?](#)

Results for {keywords}

**D Solid Research the Key**

[Kay Smith et al.](#)

Mar 10, 12:00 AM

Let's be honest, without solid research and data to back up your claims, you simply won't be able to prove your theory and apply for a grant. In my twelve years and research I have seen many people take too many shortcuts and fail when it comes time to supporting evidence with real facts. [Read More...](#)

**A DNA Animator**

[Bob Wiley et al.](#)

Mar 10, 11:33 AM

This handy little podcast is a great way to show off your personal DNA sequence. [Listen Now...](#)

**A Genome Talk Part1**

[Dr. Michael Bartholomew](#)

Mar 09, 12:10 AM

Let's be honest, without solid research and data to back up your claims, you simply won't be able to prove your theory and apply for a grant. In my twelve years and research I have seen many people take too many shortcuts and fail when it comes time to supporting evidence with real facts. [Listen Now...](#)

**V DNA Structure**

[Dr. Ed Murphy et al.](#)

Mar 09, 09:021AM



DNA is fascinating and this video shows you just how fascinating it really is. [Watch Now...](#)

**D** Document    **A** Audio File    **V** Video File

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article discussion edit history

# Main Page

**WikiAdvocacy** is a free, reader-built guide, as well as a community for advocacy. It covers every aspect of founding and growing an advocacy organization from fundraising to detailed explanations of issues, skills, and the elements of creating a registry and samples repository.

If this is your first time visiting WikiAdvocacy, we recommend reading **About WikiAdvocacy** and **How to Get Started**. We also recommend checking out the **community portal** and **help** pages.

[| About WikiAdvocacy](#) | [How to Get Started](#) | [Community Portal](#) | [Help](#) | [How to post a file on WikiAdvocacy](#) |

## Directory

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## Introduction

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[Defining Our Terms](#) -- [The Power of Advocacy Organizations](#) -- [Why Go There?](#) -- [How to Use This Guide](#) -- [History of Advocacy Organizations and Genetic Alliance](#) -- [The Kitchen Table Is a Good Place to Start](#)

## Organizational Assessment

[edit]

[Determine Goals](#) -- [Characterize Condition](#) -- [Characterize Resources](#) -- [Compare Goals and Resources, with the Characteristics of the Condition](#) -- [Considering Starting a Support Group for a Condition that Already Has One?](#)

## Organization Development

[edit]

## Organizational Structure

[edit]

[Organization's Name](#) -- [Governance Board](#) -- [Bylaws and Articles](#) -- [Tax and Finance](#) -- [Finding a Lawyer](#) -- [Working with a Lawyer](#) -- [Volunteer Committee](#)

## Resources for Development

[edit]

[Helping Your Membership Help Your Group](#) -- [Recruiting](#) -- [Internet Service Provider](#) -- [Maintaining Membership](#) -- [Taking Credit Cards on the Web](#) -- [Becoming the Organization You Imagine](#) -- [Getting Grants](#) -- [Donations](#) -- [Member Dues](#) -- [Events](#) -- [Celebrity Spokesperson](#) -- [People and Roles](#) -- [Harnessing the Resources That Are Hard to Measure](#) -- [Preparing for and Handling Publicity](#) -- [How to Obtain Donated Office Space](#) -- [Building a Website](#)

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# WikiGENETICS

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## Main Page

## Welcome to WikiGenetics

[\[edit\]](#)

**WikiGenetics** provides credible and up-to-date information on human genetics. It is a web-based encyclopedia on human genetics for the public. The content is generated by users who are allowed to view and to edit pages, frequently geneticists as well as members of lay advocacy groups. The site was initially created by Genetic Alliance in 2007 and has an advisory and editorial board.

[About WikiGenetics](#) | [Getting Started](#) | [Community Portal](#) | [How to Post a File on WikiGenetics](#) | [Help](#)

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### Basic Science

- [The Cell Cycle](#)
- [DNA](#)
- [Chromosomes in Cells](#)
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- [Chromosome Abnormality](#)
- [Gene Expression](#)
- [Allele](#)
- [Inheritance](#)
- [Genes and Their Properties](#)

### Understanding the Human Genome

- [Organization of the Human Genome](#)
- [Human Gene Expression](#)
- [Mutations: Changes in the Genome](#)
- [Instability of the Human Genome: DNA repair](#)
- [Physical and Transcript Mapping](#)
- [Polymorphisms and SNPs](#)

### Understanding Health and Disease

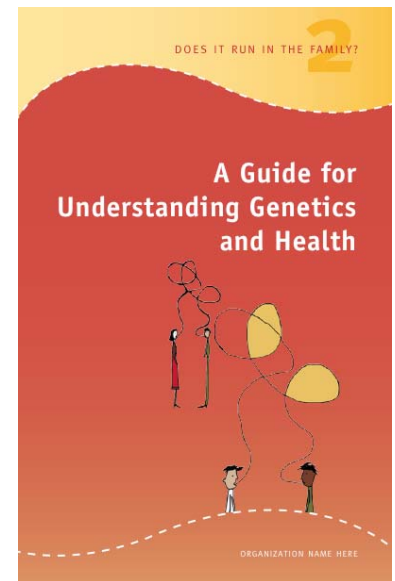
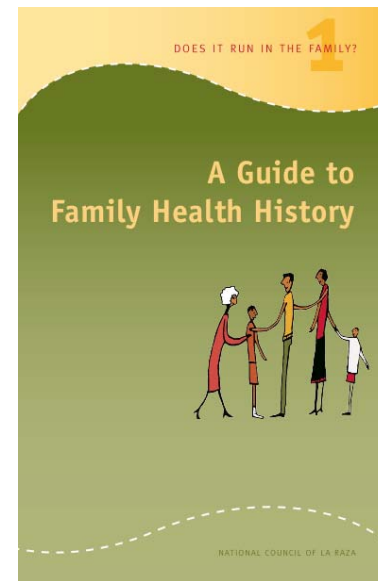
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- [Identifying Human Disease Genes](#)
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- [Single Gene Disorders](#)
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### Genetic Services

- [Family History](#)
- [Genetic Counseling](#)
- [Public Health Programs - Newborn Screening](#)
- [How to Find Qualified Services](#)
- [Consumer Genetics and Genomics](#)
- [Who's Who in Genetics - Professions & Credentials](#)

# *Does It Run In the Family?* Toolkit

- Accessibility
- Community Input
- Sustainability
- Evaluation
- Resource Sharing





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