

HOW TO RESEARCH POTENTIAL MEMBERS OF YOUR MEDICAL/SCIENTIFIC ADVISORY BOARD

Produced by the National Organization for Rare Disorders (NORD®)

Objective: To identify researchers, physicians, clinicians, or other related medical professionals with an interest in your rare disease in order to approach and recruit experts for your organization's Medical Advisory Board.

Research: Utilize Reputable Sites

1. The United States National Institutes of Health (NIH) Genetic and Rare Diseases Information Center (GARD): rarediseases.info.nih.gov.

NIH GARD provides the public with access to current, reliable, and easy-to-understand information about rare or genetic diseases in English or Spanish – and also includes a way in which to identify experts in your rare disease field.

- a. Use the search bar to search for your rare disease.
- b. At the end of each rare disease report within the “References” section, you will find citations for the original data sources.
- c. When reviewing the original data sources, you may find names of the authors, often along with their university/department affiliation and email address. Note their names, any contact information listed for them, and the title and link to their article.

2. NORD Rare Disease Database: rarediseases.org/for-patients-and-families/information-resources/rare-disease-information.

NORD's Rare Disease Database provides overviews of specific rare diseases for patients and caregivers.

- a. Use the search box to search for your rare disease¹.
- b. NORD usually acknowledges the author at the top of the report. The author is often the main expert in the disease field and a great starting point for your search.
- c. At the bottom of the rare disease report is a “References” section where you will find a list of published articles with their authors.

3. PubMed: pubmed.ncbi.nlm.nih.gov.

PubMed® is a free resource supporting the search and retrieval of biomedical and life sciences literature with the aim of improving health – both globally and personally. The PubMed database includes more than 34 million citations and abstracts for biomedical literature from MEDLINE, life science journals, and online books. PubMed was developed and is maintained by the National Center for Biotechnology Information (NCBI), at the US National Library of Medicine (NLM), located at the NIH.

- a. Search for your rare disease using the disease name, synonyms or gene name.
- b. If your search returns many published articles for your rare disease, consider adding terms such as “etiology” (disease cause), “pathology” (disease process), “treatment”, or even a specific state or country to the main search term. You can also use the advanced search feature to narrow your results.

1. NORD regularly adds new reports to our Rare Disease Report library. If your rare disease does not have a Rare Disease Report yet, please review the remainder of the guide for alternate sources of disease information.

- c. Review articles covering broader titles related to the rare disease rather than very specific ones to find authors in related disease areas. If there are very few or no articles for your specific rare disease, substitute a more common disease name that may have a similar cause, disease process, or symptoms as your rare disease. This method may locate researchers who have the experience, knowledge and interest in including your disease in their research efforts.
- d. Contact information is often available for at least one of the authors of an article found through PubMed. If you click on the article title in the search list to view the abstract or summary, the contact information can be found by clicking "+ expand" next to "Affiliations" just below the list of authors.
- e. GeneReviews (ncbi.nlm.nih.gov/books/NBK1116), located within PubMed, is another excellent resource for locating the email addresses of authors and their affiliations should a report exist for your rare disease

4. Hospital/University Departments:

Start looking into hospitals or contacts in your community. From there, you can research top hospitals, health centers, or specialists that are awarded for excellence for your specific disease. If you're not sure where to start and your search findings are too general, take a closer look at the hospitals and institutions in which researchers are affiliated from PubMed published articles and work from there.

- a. You can search for physicians or specialists in relevant department sections of the hospital website (i.e. oncology, neurology, pediatrics, hematology, etc.). A physician's profile will include contact information, specialties, research, and the specific age/disease groups they serve.
- b. If a physician's email address is not available, you can also look into their other associations/affiliations by searching their affiliation's website or for their LinkedIn profile (e.g., if a hospital website notes that they teach at Harvard, search for their professor profile on Harvard's website).
- c. You do not need to add every physician from a department to your list. Confirm that their specialties and research interests are aligned with your rare disease.

How to Organize Your Researcher/Physician Information:

1. You may wish to use a spreadsheet to organize all researcher/physician information.
2. Some potential columns include:
 - a. Name
 - b. Contact information (email address)
 - c. Geographical location (including institution/department/role and address if available)
 - d. Clinical focus
 - e. Research focus (specific disease)
 - f. Research publication/engagement with disease (title and link to research publication(s) or link to profile page if there are no published articles associated with the individual)
 - g. The website link where you first identified the medical expert (you can refer to this source in your contact with the expert, e.g., "I found your name listed in the NORD Rare Disease Report for XYZ-disease")
3. If you have an extensive list of possible advisors, it can be helpful to group the clinician and researcher information into categories including:
 - a. Domestic-based professionals (include column for state and sort by state and alphabetically)
 - b. International professionals
 - c. Interested researchers and clinicians (include those whom you may already have a connection with/have expressed interest in being part of your organization)

- d. Researchers and clinicians from the same hospital/institution (include column for that hospital/institution and sort alphabetically)
- e. Other categories that may be relevant to your group (e.g., researchers grouped by discipline)

Tips for capturing accurate information for researchers, clinicians, or physicians:

1. In general, list all researchers, clinicians, physicians, or other medical experts referenced in published articles.
 - a. Some researchers may be listed with the first letter of their first name and their last name. Copy their name and search with their credentials (e.g., “M.D.,” “Ph.D.”) to assist in finding the researcher’s contact information.
2. If you find two email addresses for one researcher, such as a university address and a hospital address, use both addresses when conducting your outreach – some experts may check one account more than another.
3. When reviewing articles, note any recurring author names, as those authors have contributed more research/publications in your disease space and may be worth prioritizing on your list for outreach.

Tips for finding contact information/email addresses for researchers in published articles:

1. Conduct a Google search for the name of the researcher, clinician, or physician along with their title (e.g., “M.D.”) or other related degrees/credentials. To target the results further, try adding “email address” after the researcher/physician’s name.
2. If you still cannot find their email listing, you can search for their office email or LinkedIn profile. If the researcher or physician has their own medical practice, note the email address for their office, especially if their personal email is not available.
3. If you can only find their office phone number, you could consider calling the number to request their email address.
4. It can be tricky to find email addresses for international researchers but use the same search tactics noted above and set your webpage to translate to English.
5. Some listed researchers on an article on PubMed/related website might not have their contact information/affiliation listed but others might. For those who do not, click on their name to find additional articles they are affiliated with. Oftentimes if they are the first author listed, they will have contact information/affiliation included.

Tips for finding additional researchers if your initial search is insufficient:

1. If you are not finding many researchers or physicians associated with your specific rare disease, consider looking into any related or associated diseases. Researchers in a related disease space may be interested in your rare disease. If your disease is listed in NORD’s Rare Disease Report, check to see if there is a section for “related disorders” that you may find helpful in identifying associated conditions.
2. Related diseases research can be conducted using the same methods suggested above.

ADDITIONAL RESOURCES:

- RareLaunch Research Ready Workshop: How to Connect with Scientists and Industry Stakeholders (learn.rarediseases.org/courses/rarelaunch-research-ready/lesson/how-to-connect-with-scientists-and-industry-stakeholders/)
- RareLaunch Webinar: Creating Your Medical Advisory Board (rarediseases.org/nord-rarelaunch/rarelaunch-resources)
- Letter Templates for New Nonprofits for Board Members and Medical Advisors (rarediseases.org/nord-rarelaunch/rarelaunch-resources/)
- Medical Advisory Board Tip Sheet (rarediseases.org/nord-rarelaunch/rarelaunch-resources)
- Medical Advisory Board Policies and Procedures Template (rarediseases.org/nord-rarelaunch/rarelaunch-resources)
- Medical Advisory Board Member Agreement Template (rarediseases.org/nord-rarelaunch/rarelaunch-resources)