

Before starting the awareness and dissemination talks

- Think on the targeted places where you plan to do the awareness and dissemination activities
- Send them a letter explaining who you are and the goals that you want to achieve;
- Inform us about the GREAT results that you got with your activity by sending an e-mail to cdgawareness@gmail.com

CDG AWARENESS AND DISSEMINATION KIT :

- Kit materials include:
 - A powerpoint with an introduction about Rare Diseases and Living with a Rare Disease (CDG in our case)
 - Fundraising and Conference presentation course

**For CDG AWARENESS AND DISSEMINATION KIT materials, please contact:
cdgawareness@gmail.com**

CONGENITAL DISORDERS OF GLYCOSYLATION (CDG) AWARENESS AND DISSEMINATION PROJECT

QUESTIONS ABOUT PRESENTATION SUPPORT CONCERNING:

- INTRODUCTION ABOUT RARE DISEASES (RD)
- THE PATIENT'S VOICE
- CONFERENCE PRESENTATIONS COURSE

CONTACT: Vanessa Ferreira (sindrome.cd@gmail.com)

- HAVING A RARE DISEASE: LIVING WITH CDG

CONTACT: Bas Holten (basesdownunder2003@hotmail.com)

TUTORIAL FOR FUNDRAISING:

- SIMPLE STEPS FOR FUNDRAISING SUCCESS

CONTACT: Andrea Berarducci (maui911@yahoo.com)

CONGENITAL DISORDERS OF GLYCOSYLATION (CDG) AWARENESS AND DISSEMINATION PROJECT

In each of the following slides, we suggest some sources of information and ideas about what you may want to discuss and highlight in your presentation...

Be aware that some information should be adapted to the country where you live. Thanks!

SKYPE FOR HELP IN ORAL PRESENTATION PREPARATION:

Skype name: cdgawareness

**PLEASE IF YOU USE THIS
AWARENESS MATERIAL
WE KINDLY REQUEST YOU
TO MENTION AS
SOURCE:**

**CDG AWARENESS DONE BY
CDG PATIENT'S VOICE**



TUTORIAL FOR FUNDRAISING:

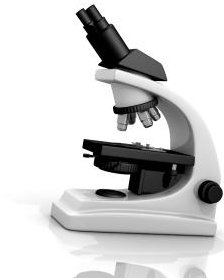
▪SIMPLE STEPS FOR FUNDRAISING SUCCESS

CONTACT: Andrea Berarducci
(maui911@yahoo.com)

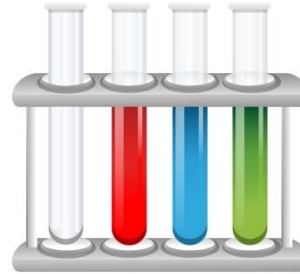
CDG PATIENT'S VOICE

AIMS:

TO INCENTIVE AND SUPPORT RESEARCH



http://www.freedigitalphotos.net/images/view_photog.php?photogid=1152



www.freedigitalphotos.net/images/view_photog.php?photogid=2280



http://www.freedigitalphotos.net/images/view_photog.php?photogid=151

**TO ESTABLISH A CDG NETWORK: PATIENTS, RESEARCHERS
AND MEDICAL DOCTORS=RESULT!**

**Simple Steps TO Fundraising
success**

Sources of Funding - Overview

- Individuals
- Foundations – Large, Community, Corporate
- Corporations – Large, Community-based
- Government

Fundraising Basics

- Set a goal
 - Identify the need
 - Be clear about what the money will be used for
- Target an audience
 - Know or learn who your audience is
 - What will attract your audience to the cause?
- Formulate a plan
 - How much money do you want to raise?
 - Who will be donating toward the cause?
 - Who can help you put this plan/event together?
 - What is a realistic time frame?

Fundraising Options

- Auctions
- Selling merchandise / services
- Themed breakfasts / dinners
- Run/Walk/Bike – a-thons
- Events with a twist... comedy night, trivia night, bowling events, dance-a-thons
- The “Non-event” event
 - A mailing or solicitation in place of an actual event
 - Cash cans, percentages of breakfast / dinner sales, etc

Selecting the “Right” Fundraiser

- Group dynamics
 - Research your target audience
 - “Think globally, act locally”
- Establish a time frame
 - Consider time, money and resources available
- Consider costs
 - Network! Look for those who may be willing to donate goods and/or services toward your fundraiser
- Identify resources
 - What materials are needed? What manpower is needed?
 - Spread tasks among volunteers according to experience, strengths and capabilities

The Details of the Fundraiser

- Identify a location – look for donated space, work with the venue coordinator
- Setting the “right” date – prepare for “seasons” and weather considerations, if applicable
- Organizing and recordkeeping – be accountable, track donors, and collect contact information for follow-up!
- Finding volunteers – who and how can people help?
 - Churches, civic groups, schools, etc
- Set a schedule
 - Be comprehensive, include details, track progress
- Invitees and special guests
 - Think of anyone who will draw the audience to the cause
- Contingency plans – always have a back-up plan

Community Fundraising

- Involving the community – focus on everyone, not just the “big” players in the community
- Make things happen – start small, get people on board, and build group enthusiasm
- Work with your community Board – build awareness
- Find local sponsors – find sponsors, co-sponsors and make opportunities for recognition
- Promote locally – pre-event coverage as well as post-event coverage; give yourself at least 3 months to promote your fundraiser
- Social networking – post event information, pictures, videos and blogs

The Budget

- Assess costs – “Raising money costs money”
 - Typical expenses – food/refreshments, speakers/equipment, travel/lodging, items to be sold/raffled, event supplies
- Budget for expenses – Determine how you will spend money and how you will make money
 - Sell tickets, hold raffles, auction items, etc
- Find sources of funding
 - Develop a list of prospects
 - Individuals, businesses, civic organizations, government agencies, foundations and trade associations

Fundraising Tools

- Communication infrastructure
 - Determine how technically savvy your group is
 - Identify technology available to the group, as well as budget or equipment that will be necessary for your communication strategy
- Know who to contact
 - Make a list of contact persons for each aspect of planning
- Using a website for fundraising
 - Post pictures, videos, interviews and blogs
 - Social networking, email and facebook
- E-fundraising
 - Low cost way to generate revenue in support of a specific cause
 - Causes.com, Justgive.org, etc

Spreading the Word

- Advertising – Define your advertising needs:
 - Radio – PSAs, on-air interviews/appearances
 - Internet & Email – post stories, pictures & videos
 - Online newsletters – always link back to your website
 - Signs, Flyers and Posters – simple, clear and strategic placement
 - Promotional Activities – free giveaways, kickoff event, photo opportunities and print stories prior to the event
 - Print – use community resources, newspapers, grocery stores, community centers, etc
 - Visual Marketing – “A picture is worth a thousand words”
 - Design the graphics, text and photos for your event in a visually appealing and clear way
 - Hire or recruit a professional to donate services to help

Alternative Ways of Fundraising

- Foundations
- Corporations
- Grants
- Other major donors

Foundations

- Can be public, private, corporate or government foundations
- Typically fund worthwhile causes and activities including educational, scientific, environmental, political and charitable needs
- Foundations are typical funders of special projects and do not fund ongoing operating expenses
- Seeking foundation grants require well established plans and submission of a proposal, including measuring evaluation and follow-up
- Research the Foundation Center – www.fndcenter.org

Corporations

- Approaching Corporations
 - Who do you know?
 - Build relationships
 - Give something back – public image, corporate recognition
- Employee Donations
 - Many companies have employee contribution programs or “matches”
 - Contact the company’s Human Resources and to discuss matching gift programs (either adding to or establishing a new one for your cause)
- The United Way – currently contributes to 1,300 community-based organizations

Grants

- Finding grants
 - Do your research, be aware of geographical restrictions, guidelines of the funder, application criteria and whether your needs are a match for the funding programs available
- The application process
 - Collect data, be specific, state your cause, following grant guidelines, develop collaborations and support, prepare the presentation
- Timing and follow-up
 - Grant funding is competitive, prepare reasonable time-lines
- Corporate grants – make sure that your cause is a good match for the corporation
- Federal grants – search for grants applicable to your cause;
www.grants.gov

Measuring Success

- Evaluate fundraising efforts – post-event evaluations... “what worked” and “what needs improvement”
- Evaluate the process – did you make the right choices, what are areas that you can measure for future success
- Make improvements – seek feedback, judge your weak points, focus on the positives
- Fundraising wrap-up – maintain a log of resources and event highlights, prepare for the future, report results
- Say “thank you”, “thank you”, “thank you” to everyone who helped make your event successful, ensure that proper acknowledgements are made for “repeat performances”!

Conference presentation Course



http://www.freedigitalphotos.net/images/view_photog.php?photogid=1738



- **IDEAS TO REACH A GREAT TALK**

Tutorial by Vanessa Ferreira
(sindromecdg@gmail.com)

Points to consider:

- Effective public Speaking
- Anatomy of a seminar
- Common mistakes in slide preparation

Effective public Speaking

- Voice Projection

(Speak loud and clear, but dont shout!)

- Make eye contact with your audience

- Be animated and enthusiastic about your work

To avoid this:



http://www.freedigitalphotos.net/images/view_photog.php?photogid=1499

How Do I Motivate Others?

- Verbalize an Inspiring Vision and Mission
- Project a Courageous Spirit
- Behave with Enthusiasm

Anatomy of a seminar

- It's important to structure your content!
- Structure helps memory and orientation.



http://www.freedigitalphotos.net/images/view_photog.php?photogid=659

Anatomy of a talk

It's like a sandwich!



http://www.freedigitalphotos.net/images/view_photog.php?photogid=2365

INTRODUCTION

BODY OF THE TALK

- **EVIDENCE**
- **INFORMATION**
- **ARGUMENT**

CONCLUSION

INTRODUCTION

- Name / Role
- Purpose of Conference
- Agenda
- Elucidate the public if they can interrupt you during the talk or if the questions should be at end

INTRODUCTION

- **Your purpose and/message**
 - What will they learn once they leave your talk that they do not have now?
- **Importance of the message**
 - Why should they bother?
- **Orientation**
 - Starting point, what will be covered, where end?

BODY OF THE TALK

To organise your:

- EVIDENCE
- INFORMATION
- ARGUMENT

Into a logical flow.

CONCLUSION

- State message (again)
- Summarise
- Why it is important
- Thank them (motivate the audience to questions!)

SECRET IS....

PLAN

PLAN

PLAN



PRACTICE

PRACTICE

PRACTICE

Common mistakes in slide preparation

- Time: 1 minute per slide! And do not prepare long talk (25-30 minutes)
- Choice of font and point size
- Choice of text color
- Improper use of animation

Choice of font and point size

- 24 point font use for text
- 32 point font use for list of points
- 48 point font use for titles

Choice of text color

- In fact the option to use color is very subjective. Although, it is important to be aware about the combination of colours that you use:
 - Blue and black it is a terrible combination, like yellow and white

Then, we cannot forget that 7% of male population is red/green blind

Improper use of animation

- Use the animation only when required, otherwise it can distract.
- And make sure that you trained the use of the animation .

GOOD LUCK!!!!!! AND....



http://www.freedigitalphotos.net/images/view_photog.php?photogid=2734

Bibliography:

Smith R. How not to give a presentation. *British Medical Journal*, 2000, 321:1570–1571.

<http://www.weizmann.ac.il/mcb/UriAlon/nurturing/HowToGiveAGoodTalk.pdf>