IBD Family Education Day Planning Guide

www.KidsIBD.org
www.CDHNF.org
www.NASPGHAN.org

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INTRODUCTION
The Children's Digestive Health and Nutrition Foundation (CDHNF) and the North American Society for Pediatric Gastroenterology, Hepatology and Nutrition, are pleased to provide you with some basic planning tools for use in preparing for your next IBD Family Education Day. The goal of an “IBD Family Education Day” is to give pediatric and young adult patients and their families a place to learn more about IBD in a comfortable and meaningful environment where they can ask questions and get answers, and meet with other patients and families who have similar problems. Use this to supplement your own expertise and give you more time to think about providing the best quality program for your participants.

FORMAT /PARTICIPANT PROGRAM
Planning an Education Day requires the coordination of many details. This includes determining the date and time of the program, the format, the location and the participants, speakers and audience. Identifying the goals and objectives of the program at the onset will help the rest fall into place. Determining the date and time of the program is important. Avoid religious or school holidays. Never have an education day on Super Bowl Sunday! Determine what other events may be happening in the area and at the facility where the event is occurring. Weekends often work well for families to attend these programs. Whether it is a Saturday or Sunday - may be determined by the region of the country where the event is held. The length of the program should reflect the needs of the participants.

The format of the Education Day will vary based on size of your audience, your goals for the day and the needs of your audience. Many centers have developed diagnosis specific education days and inflammatory bowel disease is a diagnosis that lends itself to a didactic type education day. Others have combined a fun activity or outing with education and the opportunity for networking and support for children and their families.

The actual program agenda may vary and should reflect the needs of the audience. Most education days will include content that includes the following:

- Overview
- Treatment
- New therapies
- Research

The sample program and flyer are provided as an example of an agenda. It is important to have a moderator for this type of program.

Flyer Example

Growing Up With IBD
A Forum For Parents and Children
The Children’s Hospital
Stokes Auditorium, 34th Street & Civic Center Boulevard
Saturday, February 26, 2006
9:00 A.M. – 1:00 P.M.

Life isn’t always easy… especially for the thousands of youngsters who have inflammatory bowel disease (IBD). But kids can still be kids… even with IBD. A panel of health specialists will explore the impact of living with Crohn’s disease and ulcerative colitis. A unique group of experts … teens who suffer from IBD... will talk openly about how they cope with their disease.

"Introduction and Welcome"
Walter Scott – Director, Inflammatory Bowel Disease Center

"Pediatric IBD 101"
Donald Jones, M.D. – General Hospital for Children

"New Therapies in IBD"
John Smith, M.D. – Children’s Hospital

"The Pediatric IBD Center and You"
Thomas Jones – Chicago Hope Hospital

"Behavioral Health and IBD"
Jake Chide, PhD

"Surgical Options and IBD"
Daniel Boone, M.D. – General Hospital for Children

Facts from your Friends – IBD Patient Panel
Kate Davis, MSN, CRNP – Children’s Hospital

Please join us. This seminar is FREE.
Complimentary parking at the Wood Center Parking Lot.
IBD Education Day

- 9am to 1pm
- Overview of Pediatric IBD
  – James Baldwin, MD, Hospital for Children
- Nutrition for IBD: Important questions and answers
  – Cheryl Landis, MD, The Children’s Hospital of Carlisle
- Living Day to Day with IBD
  – Karen Riley, PhD, New Bethlehem Children’s Hospital
- New therapies for IBD
  – Aziz Shafi, MD, Chicago Mainline Hospital
- Facts from your Friends - IBD Patient Panel
  – Sarah Parton, MSN, CRNP, Children’s Hospital of Las Vegas

Other popular topics include:
- The role of surgery in IBD
- Laparoscopic surgery in pediatric IBD
- Research, what’s new, what’s coming
- Transitioning to an adult gastroenterologist
- Preparing and undergoing endoscopic exams

Remember to keep the length of the presentations to 20 to 30 minutes and to limit the number of presentations to four or five for a morning or afternoon session. A combination of lectures in the morning and breakout sessions in the afternoon has been a popular format in some areas. Others have combined several lectures with one breakout session at the end.

Workshops, breakout sessions or roundtable discussions provide an opportunity to present topics that may be of interest to subgroups of the audience. It also provides an opportunity for families to meet others who are in similar situations. Topics for this type of presentation could include:

- Insurance issues
- Nutritional interventions – e.g. nasogastric tube feeding
- Complimentary medicine
  - Herbal medicine
  - Acupuncture, acupressure
- Clinical trial information
- Learning to swallow pills
- Psychosocial support
- Transitioning to an adult gastroenterologist
- Preparing for the transition to college
- Sexuality for adolescents

Alternative education programs should also be considered. Kids Day occurs annually in Miami, Fl. For this event, families are invited to Dave and Busters Restaurant. Everyone participates in the games and activities of the site. A meal is provided. A pediatric gastroenterologist attends and provides a program for the parents and a pediatric psychologist meets with the patients. This program is well attended and achieves 2 goals, education and support.

Opportunities to attend sporting events such as a baseball game or going to an amusement park as a group provide opportunities for networking and support. It is also an opportunity for informal education when practitioners attend and interact with the patients and their parents.

FUND-RAISING/ SPONSORS

You probably have a list of potential sponsors at hand. If not, it can easily be developed from a list of pharmaceutical, diagnostic and equipment representatives that service the IBD area. Make yourself aware of which company is in a phase III clinical trial of a drug or releasing a piece of diagnostic equipment or supplies as they will be more likely candidates for larger contributions. In addition, you have individual donors, patients, local groups and the Crohn’s and Colitis Foundation that have common goals or service your facility that might contribute or even cosponsor your event.

Your sponsorship request should position your event and your organization as an important and successful investment in the community.

Often potential sponsors will want to see a sponsorship proposal. Sponsorships proposals will need to address:

- Goals of the event
- A description of the event / related groups or organizations to be sponsored
- Attendee demographics
- Use of logos and promotional material
- Advertising plan for the event
- Benefits to the Sponsor in marketing terms
Remember that potential sponsors receive many requests for money, so tying your request to the strategic goals of the particular event as well as your organization will help the recipients know exactly what they are sponsoring. In addition, make sure that the solicitation is managed properly so you don’t have potential sponsors who become overwhelmed or confused by repeated solicitations from different people in your organization.

SPEAKERS
Carefully select your speakers based on their areas of expertise. Reinforce with them the level of understanding of the audience and the objectives of the presentation. A diverse panel of presenters adds to the dimensions of the overall program. Potential speakers could come from the following disciplines:

- Pediatric gastroenterology
- Pediatric surgery
- Pediatric GI nursing
- Pediatric Nutrition
- Pediatric Psychology
- Social work
- Child life

AUDIENCE
Patients, family members, and friends of the patient all may be interested in coming to an event. In addition, medical and allied health staff of referring physicians might also be interested in attending.

HANDOUTS
The attendees of any presentation appreciate handouts, even if it is a Power Point Handout of the presentation that allows for note taking. Consider among the possibilities:

- A syllabus of the event detailing speaker presentation and slides
- Handouts from non-profits such as NASPGHAN/CDHNF or CCFA
- Use a reprint from one or more of the presenter’s professional papers that touch on the subject matter.
- Websites that may be of interest to the participants
- Handouts from participating sponsors that are appropriate

LOCATION
The location of the program is important. A centrally based location may increase attendance. Potential sites include:

- Hospital
- Hotel
- Restaurant
- Conference facility
- School
- Church

The budget may determine where an education day is held. Many education days are held at a host hospital. This may be the easiest for the staff. No matter where the education day is held it is important to consider the following:

- Parking – if there is a charge for parking, is there a way to provide complimentary parking to the participants?
- Accessibility for the disabled
- Is the space adequate for your anticipated audience?
- What else is occurring within the facility on the same day?
- Audiovisual capability
- Space for children’s activities that is separate from the formal presentations
- Auditorium space
- Breakout room space
- Catering or dining capabilities

SIBLINGS PROGRAM
It is important to offer a program or childcare for siblings attending an Education Day. Even if it is not your intent to provide for this, know and anticipate that families will
bring siblings to the program and may expect help in entertaining their children. Resources for childcare include:

- Child life
- Staff volunteers (nurses, support staff)
- Adolescent volunteers (provide community services letters)
- Hospital volunteers
- Family and friends

**ACTIVITIES FOR CHILDREN**

The younger audiences will need activities to keep them occupied. It is important in your planning that you consider their needs, the appropriate space and staffing for their activities. Don’t forget your volunteers who can provide anything from baby-sitting to leading more formal game activities. You should plan for different ages including children as young as 2 and teenagers. Think about including age appropriate:

- Games
- Arts and crafts
- Videos/DVDs
- Educational games such as:
  - IBD Jeopardy
  - IBD Wheel of Fortune
  - IBD Charades

**FOOD AND BEVERAGE**

You need to be aware of the facility policies related to preferred vendors, and the ability to provide snacks and/or meals to your participants. Things to consider are:

- Location of food and beverage. Separate from presentations is always preferable.
- Specific food and beverages for the children.
- Make sure food has appropriate tables and settings and is handled effectively.
- Consider buying your snacks and beverages in bulk ahead of the event to avoid excessive catering costs.

Obviously, consideration of IBD patients and families is important when selecting foods. Avoid foods that contain nuts and snacks that have popcorn. Soft drinks, juices and water along with coffee and tea for adults are generally appreciated.

**STAFFING**

Make sure you consider using your volunteers to back up your nursing and appointed staff coordinators. This can go a long way towards keeping your overall costs down.

**A sample menu for a morning program might include:**

**BREAKFAST:**
- Coffee and tea
- Juice
- Water
- Mini bagels, danish, donuts and donut holes
- Individual packets of cream cheese, butter or jelly
- Yogurt
- Fruit

**BREAK:**
- Coffee and tea
- Soft drinks
- Water
- Pretzels, potato chips (individual bags)
- Fruit
- Cookies

**LUNCH:**
- Sandwiches
- Pretzels or chips
- Beverages
- Fruit
- Cookies, etc

**PROMOTION AND ADVERTISING**

Get the word out about the program. It is important to advertise and to identify your customers. There are many ways to advertise programs:

- Mail to patients/families – send flyers to all your patients with IBD
- Post flyers announcing the program in outpatient areas and the endoscopy suite. Include satellite offices and other sites where patients may frequent.
- Website – post the event and teasers (samples of talks) on your website.
- Other practices – send flyers for distribution to other pediatric GI practices in the region.
- Email blasts – if you have email listings for colleagues (ie: Pediatric Gut Club) – utilize this list to advertise the event.
- Newsletters – include in hospital, specialty practice and CCFA newsletters
- Media – many local news programs will advertise events free of charge
- Print media – local newspapers will include in “Upcoming Events” free of charge or for a nominal fee.
Make sure your event has a catchy title with a subtitle that explains the benefit of attending the event. “How to’s” and “tips for” as introductory phrases help answer the questions of “why or so what” often in potential attendees minds.

EVALUATION

Ask participants to complete an evaluation of the event at the end that rates everything from food to presentations. This allows you to evaluate your strengths and weaknesses and provides another opportunity for participant feedback.

ADDITIONAL RESOURCES

• The Children’s Digestive Health and Nutrition Foundation (CDHNF) with the North American Society of Pediatric Gastroenterology, Hepatology and Nutrition are the leading providers of information for pediatric gastrointestinal, liver and nutritional issues. By accessing the web sites you will be able to find additional resources to download and print for participants.
  http://www.kidsibd.org/
  http://www.cdhnf.org/
  http://www.naspghan.org/

• National Institutes of Health - The Digestive Diseases site includes information on Crohn’s and other digestive diseases supplied by the federal government’s National Institute of Diabetes, Digestive and Kidney Diseases at the NIH.
  http://digestive.niddk.nih.gov

• The Crohn's and Colitis Foundation of America is a non-profit, volunteer-driven organization dedicated to finding the cure for Crohn's disease and ulcerative colitis
  http://www.ccfa.org/

• The United Ostomy Associations of America, a new national organization of affiliated, nonprofit, support groups who are committed to the improvement of the quality of life of people who have, or will have, an intestinal or urinary diversion.
  http://www.uoa.org/

• The Professional Convention Management Association (PCMA) is a nonprofit nonmedical international meeting planning association whose mission is to deliver breakthrough education and promote the value of professional convention management.
  http://www.pcma.org/

SAMPLE BUDGET

Below is a sample budget with line items that should be considered when planning an education day. (Rates and prices will vary depending on where you hold the event)

<table>
<thead>
<tr>
<th>Item</th>
<th>Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>Speaker Honorarium (7 Speakers at $100 each)</td>
<td>$700</td>
</tr>
<tr>
<td>Travel Expenses</td>
<td>$200</td>
</tr>
<tr>
<td>Hotel Rooms</td>
<td>$300</td>
</tr>
<tr>
<td>Food/Beverage Continental Breakfast</td>
<td>$8.00/person*100 participants</td>
</tr>
<tr>
<td>Coffee and tea</td>
<td>$4.00/person</td>
</tr>
<tr>
<td>Soft drinks</td>
<td>$1.00/can</td>
</tr>
<tr>
<td>Break</td>
<td>$5.00/person</td>
</tr>
<tr>
<td>Audiovisual Equipment</td>
<td></td>
</tr>
<tr>
<td>Laptop Computer</td>
<td>$100.00</td>
</tr>
<tr>
<td>Podium</td>
<td>$70.00</td>
</tr>
<tr>
<td>Screens</td>
<td>$100.00</td>
</tr>
<tr>
<td>Projector package</td>
<td>$225.00</td>
</tr>
<tr>
<td>Flip Chart Package</td>
<td>$100.00</td>
</tr>
<tr>
<td>Laser Pointer</td>
<td>$80.00</td>
</tr>
<tr>
<td>Labor for setups</td>
<td>$250.00</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>$1,815.00</td>
</tr>
</tbody>
</table>

*100 participants
## Program Evaluation Form

This program had a number of education objectives; to what extent did the speaker(s) meet those objectives?

*(please circle the number that best reflects your view: 1 = poor, 5 = outstanding)*

<table>
<thead>
<tr>
<th>1. Overview of Pediatric IBD</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>2. Nutrition for IBD: Important Questions and Answers</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>3. Living Day to Day with IBD</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>4. New Therapies for IBD</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>5. Facts from your Friends-IBD Patient Panel</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>6. Transitioning to an Adult Gastroenterologist</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

7. As a result of this program, do you feel that you:

- Increased your knowledge? [ ] Yes [ ] No
- Learned information that will change the way you manage IBD on a daily basis [ ] Yes [ ] No

8. Please provide your e-mail address, so that we may stay in touch with you for future programs

   Email: ________________________________________________________________

9. Please provide general comments about this educational program or suggestions for future materials.

   ________________________________________________________________

   ________________________________________________________________

   ________________________________________________________________

   ________________________________________________________________

   ________________________________________________________________

   ________________________________________________________________
IBD FAMILY DAY PLANNING GUIDE CHECKLIST

Below is a reminder form that you can use for any upcoming events. Make multiple copies and add your own reminders in the blank space at the bottom of the page.

<table>
<thead>
<tr>
<th>Date</th>
<th>Time</th>
<th>Location</th>
<th>Format</th>
<th>Goals</th>
<th>Audience</th>
<th>Fundraising/Sponsors</th>
<th>Program</th>
<th>Speakers</th>
<th>Handouts</th>
<th>Sibling Program</th>
<th>Activities for Younger children</th>
<th>Food and Beverage</th>
<th>Exhibits</th>
<th>Promotion</th>
<th>Communication</th>
<th>Contracts</th>
<th>Room Rental</th>
<th>Decorations</th>
<th>Audiovisual</th>
<th>Custodial</th>
<th>Event Staffing</th>
<th>Promotion and Advertising</th>
<th>Budget</th>
<th>Evaluation</th>
</tr>
</thead>
</table>

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