

2006 National Conference Survey Results

Published on The Carcinoid Cancer Foundation (<http://www.carcinoid.org>)

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2006 National Carcinoid/NET Patient Conference

PORTLAND, OREGON

Friday, September 29 and Saturday, September 30, 2006

362 People Out Of 380 Registrants Attended the Conference

(104 medical professionals attended the Saturday Physician Symposium)

Friday, September 29, 2006

215 (60%) respondents (not all respondents answered every question)

1. Overall quality of today's conference? 204 responses

Excellent	175	86%
Good	28	28%
Fair	0	0%
Poor	1	0.5%

2. Right time of year for event? 206 responses

Excellent	179	87%
Good	23	11%
Fair	4	2%
Poor	0	0%

3. Quality of facility? 207 responses

Excellent	154	74%
Good	47	23%
Fair	6	3%
Poor	0	0%

Saturday, September 30, 2006

139 respondents (not all respondents answered every question)

1. Overall quality of today's conference? 124 responses

Excellent	97	78%
Good	25	20%

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Fair	2	2%
Poor	0	0%

2. Right time of year for event?

124 responses

Excellent	108	87%
Good	12	10%
Fair	3	2%
Poor	1	1%

3. Quality of facility?

123 responses

Excellent	99	81%
Good	19	15%
Fair	5	4%
Poor	0	0%

Categories of Individuals Attending the Conference

Friday, September 29:

230 responses

Diagnosed with carcinoid	112	49%
Diagnosed with another NET	15	6%
Caregiver	73	32%
Health care professional	6	2.6%

(these included doctors, nurses, research assistant, clinical scientist, nurse practitioner)

Other	5	2%
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(these included MEN1 patients, family members, wife, husband)

Patient & health care professional	8	3.4%
Caregiver & health care professional	11	5%

Saturday, September 30:

132 responses

Diagnosed with carcinoid	73	55%
Diagnosed with another NET	10	8%
Caregiver	37	28%
Health care professional	4	3%

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Other	4	3%
Patient & health care professional	2	1.5%
Caregiver & health care professional	2	1.5%

Of the patients who attended the conference, 88% have carcinoid cancer and 12% have other neuroendocrine tumors (NETs).

General comments:

- Well organized and run.
- Time constraints are a problem maybe?
- All is necessary to meet the needs of all individuals.
- You do a great job - we enjoy these seminars and meeting other carcinoid patients.
- The conference is well organized. You really did a great job.
- You all did a great job of setting this up.
- This conference was very organized. I love the notebooks with indexing. Good job!
- Did not like lunch.
- This has been an amazing conference today. You are to be congratulated on bringing together this faculty - so knowledgeable and good presentation skills -a dynamite combo! Thank you!
- Lots of information but it will be online so I can feed my brain slower.
- Great job.
- Thanks for using the color codes on our nametags.
- Overall, I'm pleased and feel informed.
- Overall this has been great. We especially enjoyed meeting other 'young' patients like my son.
- This was excellent! I don't see how it could be improved.
- You are doing a phenomenal job. Thank you.
- Excellent conference. I learned a lot but I'm afraid most of the presenters were too technical, but I guess there's no other way to present.
- Overall very well done!
- Reception food was super!!
- I felt that the conference was very well put together. You did a good job. The Double Tree staff handled everything efficiently.
- It's great to see the advancements being made. This may be very hard to improve on.
- Congratulations on keeping your time frames and keeping things moving!
- PNWCC worked their tails off - great job. Food needs improvement other than that so far best we have attended.
- I have attended and participated in several conferences during my life. This is one of, if not, the best of them all!
- Too cold, people had to run to their rooms to get coats.
- Do we really need to introduce each speaker more than once with all his credentials?
- Really appreciated the notebook with outlines and summaries. I was going to suggest having one page with presenters' info and suddenly it was there on our table!
- This will be "hard to beat" excellent. Thank you.
- Great job!
- Really great seminar.
- Seating arrangement - prefer tables facing speaker and box lunches. Tell people to turn off cell phones.
- Very well run and organized.
- First class conference! Extremely well organized, professional, awesome food, impressed with your ability to keep the sessions on time. Congratulations! Fabulous, invaluable information. Thank you!
- The binders were great! Thanks!

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- Program offers “one-stop shop” for receipt of highly technical, very timely, cutting-edge information on rare diseases. I don’t think this information could be (can be?) replicated outside this forum – personally very enlightening!
- Extremely impressed with the way this has been run. This is a tremendous undertaking, and I for one appreciate all the hard work and time that went into this. Thank you!
- Overall VERY impressed with quality of program.
- The audio was great! The venue was perfect except size limited.
- Has been great for us.
- Overall excellent information gained. See you in VA!
- I feel this is excellent and I am impressed and grateful for all these professionals to attend and share their info. Thank you.
- Stay the course!
- This was very well done, excellent handouts.
- Very interesting and helpful. Thank you for putting on this conference.
- Good overall presentations on wide variety of associated topics.
- Really good – glad you did do it.
- Overall was very information and great job!
- Very good conference, thank you. The doctors did very well to make a lot of technical info understandable. I also appreciated their availability and willingness to talk with the conference attendees.
- We do appreciate all the effort and time everyone put into the conference. Thank you!
- Very well done, Great work!
- Thanks for a successful conference!
- Actually I don’t see how future events of this type can be improved. Super conference!
- Great job.
- Excellent job!
- It was wonderful. Thank you.
- This has been one of the most information conferences. Having as many different doctors and ideas has been rewarding. Well done!
- Great.
- You guys did a great job!
- Great job.
- Keep up the good work – this was my third annual and so far, the BEST!
- Hard to beat! Overall excellent content and format.
- Good job overall.
- Keep up the good work! Thank you!
- The organizers did a fantastic job – great site, good food, wonderful speakers and topics. Thank you.
- Tough act to follow – A TERRIFIC/ outstanding job that reflected incalculable hours spent, very committed group.
- The organization of the event was fantastic! Great job!
- It would be hard to improve. I enjoyed it immensely.
- Great conference!
- Overall, I enjoyed the conference. Thank you for all of your efforts.
- Meals and general food services were very good.
- It was perfect.
- Thank you so much! It was awesome!

Do you have suggestions on how we can improve future events of this type?

In summary, there were a few suggestions that were given the most often. In order of frequency they were:

- Too technical -- The presentations were too technical. Participants were often unfamiliar with terminology and are seeking more practical and less technical information.
- More time for questions and answers -- Participants want more time allocated to questions

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and answers. This overall suggestion also included complementary recommendations for sessions where the doctors only answer questions, rather than give presentations, and the suggestion to put questions in writing. This would enable physicians to select the questions in advance and to eliminate excess movement around the room.

- More breakout groups - Smaller groups seem to be favored by many who made comments. Some said they would like to see groups by type of carcinoid tumor.
- Have longer sessions- Fewer topics should be covered and there should be more time allocated for each session.
- Avoid duplication amongst speakers - Participants feel there needs to be more coordination to avoid duplication of topics amongst speakers.
- Glossary of terms -- In keeping with the suggestion that much of the information was too technical, participants feel that a glossary of terms in the binder would be very helpful. The glossary should also include a list of all abbreviations used by physicians.
- Bios of speakers - Put biographers of speakers in the binders that are handed out upon registration. This would help avoid lengthy introductions of speakers and repetition of introduction of those who speak on more than one panel.

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