



Society for Ear
Nose and Throat
Advances in Children

*Newsletter
Fall/Winter 2009*

Editor's Note



Welcome to the fifth edition of the annual SENTAC Newsletter, and the first e-newsletter. You can read this on-line, download it and read it in your travels, forward it to a colleague, and share the wealth that SENTAC has to offer.

In this edition, you will find information about the upcoming 37th annual meeting of SENTAC which will be held in Salt Lake City, Utah from Thursday, December 3 through Sunday, December 6, 2009. For a look at the complete program and to register, go to www.sentac.org (isn't this easy?) Thanks to Joan Arvedson and the members of the Program Committee, we have a varied program of scientific sessions, panels, courses and posters with something to interest all of our members from their respective disciplines. You will find a summary of the program in Joan's article in this newsletter. Please look inside for some beautiful pictures of Salt Lake City as well as some of the sites of interest in the city and environs (www.saltlakecity.com/attractions). Social activities and excursions are also listed in the program, with time to enjoy SENTAC colleagues and friends.

Anthony Magit, our Secretary, summarizes last year's terrific conference in Boston and our Treasurer, Udayan Shah, gives us a brief overview of our financial status. Three of our international members/colleagues, Dr. Anthony Ysunza of Mexico, Dr. Marc Pellicier of Spain and Dr. Ari Rowe from Israel give their perspectives on SENTAC and what it has meant to them. As we look toward the future of SENTAC and expanding our reach, the concerns and opinions of our international members are important to keep in mind.

We have a section listing new members and one in which we remember one distinguished member who, sadly, is no longer with us.

Two interesting essays in this issue: I have asked Dr. Chris Feudtner, pediatrician and medical ethicist, to write a piece for us, and he has written beautifully about how value judgments influence our technical approach to problem solving in pediatric medicine. He touches on issues of quality of life and cost-effectiveness in ways that influence healthcare decision making.

I know many of us have seen children adversely affected by their medical and/or developmental challenges, and yet some children seem to thrive despite their challenging circumstances. I've asked psychologist Dr. Marsha Gerdes to write about resilience in children shedding light on the mechanism of resilience and on what can be done to foster it.

I think you will find both of these essays

thought-provoking and perhaps we can continue a dialogue at our meeting in Salt Lake City.

Looking forward to seeing you there!

Cindy

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Message from the Program Chair

37th Annual SENTAC Meeting



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The time is fast approaching for the 37th Annual SENTAC Meeting that will take place in Salt Lake City, Utah, December 3-6, 2009, at the Marriott Downtown Hotel. The SENTAC website has information about the hotel. You can make your reservations quickly and easily online. The Chamber of Commerce statement goes something like this, "Combining the amenities of a major metropolitan area with the friendliness of a small, western city, Salt Lake City is an ideal location for group travel. A beautiful, safe, and vibrant city, Salt Lake combines unparalleled access to natural recreation, a bustling economy, dynamic nightlife, remarkable history, warm hospitality, and Utah's greatest snow on earth."

We opted for the convenience of the meeting in a downtown hotel. Those of you who want to head out for ski areas will find them readily accessible. Enjoy!

First I want to thank the program committee members: Sam Daniel, Karen Gordon, Andy Hotaling, Roxanne Link and Harlan Muntz. Members did blind reviews of all abstract submissions and decisions were made regarding acceptance on the basis of ranking interest, methodology, and content. A special *thank you* goes to Marc Steele, webmaster, who developed the process and provided assistance as needed.

We had about the same number of abstract submissions as last year in Boston. Many of you will recall that great meeting, and Salt Lake City promises to be another great meeting. There is a wide variety of topics to be covered during the scientific meeting. We will make the posters an integral part of the scientific meeting as they are often even more useful than the podium presentations, and I'm not taking anything away from those podium presentations!

We will have opportunities to participate in multi-disciplinary discussions in varied venues to include: (1) question time following every 3-5 podium presentations grouped by topics as much as possible, (2) break times of 30 minutes to view posters and talk with those presenters, as well as talk with vendors; (3) poster wine-and-cheese reception prior to the banquet Friday evening; (4) panel sessions in a point/counterpoint format (topics below); (5) Friday lunch breakout sessions during which time we will examine some "21st Century Challenges" with broad focus issues in care for children.

We are privileged that Dr. Ed Clark, Chair of Pediatrics at the

University of Utah and a pediatric cardiologist, will deliver the Arthrocare sponsored lecture. He is also medical director for Primary Children's Medical Center in Salt Lake City. This is the second year of a five year grant for which we are grateful to Arthrocare. Dr. Clark epitomizes the theme of "Enhancing the Care of Children." He will share with us his involvement in a national children's study that is in process of being launched to study genetics and environmental factors. Dr. Clark told me that this study will yield the "best studied children on earth." This will do what the Framingham study did for adults. The website is www.nationalchildrensstudy.gov for you to check out. It has taken 10 years to get this study launched: Epidemiology of children's diseases to include prematurity, obesity, and many others. There will be case control groups and subsets for research, which could give opportunities for SENTAC members to get involved. He will speak prior to a break time, so you will be able to talk with him right after his lecture.

Panel sessions are being planned in a point/counterpoint format to focus on controversies or differences in practice and to give major time for audience members to raise questions and add their own evidence. Topics include: Gaps in Health Care for Children, Down Syndrome, Drooling and Aspiration, Psychosocial Issues with Hearing Loss, and Post-op Care of PE Tubes.

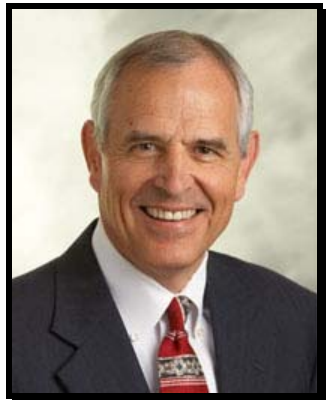
We look forward to honoring colleagues for the following awards: (1) Robert Ruben Award for Scientific Achievement: Blake Papsin, MD; (2) Sylvan Stool Award for Teaching and Service: Michael Cunningham, MD; (3) Steven Gray Humanitarian Award: Connie Lusk, RN. We will have the privilege of listening to their lectures. Please congratulate them. I also urge you to nominate colleagues for these special awards for 2010.

(Nominations should be made to David Parsons, President, at parsons@aol.com.)

The Saturday afternoon social program is being finalized. Further details will become available on the website. Plan to join your colleagues for a relaxing and fun time. On Sunday, we have a solid set of podium presentations, panels and the Sylvan Stool Award lecture. I hope that most of you will be able to arrange travel to stay until noon on Sunday. I look forward to seeing old friends and colleagues, making new friends, and gaining new information and insights into the myriad areas of ear, nose, and throat advances in children. Travel safely.

"We opted for the convenience of the meeting in a downtown hotel. Those of you who want to head out for ski areas will find them readily accessible. Enjoy!"

Message from the President



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Hi! The 2009 meeting of the Society for Ear, Nose, and Throat Advances in Children (SENTAC) will be held December 3 to December 6, at the Salt Lake City Marriott Downtown Hotel. Our 37th annual meeting promises to be a fun and educational experience. SENTAC remains for many of us one of the most enjoyable meetings and societies in all of medicine.

If you have not registered, visit www.sentac.org and get on board!

Dr. Joan Arvedson, Program Director/Past President, and Dr. Harlan Muntz, local arrangements, have worked hard to organize an outstanding program to meet the educational needs of this unique society representing otolaryngologists, pediatricians, speech pathologists, audiologists, nurses, nurse practitioners and industrial leaders with concerns for children's safety.

For those of you not familiar with SENTAC, it is a most distinctive society founded in 1973 as an interdisciplinary professional organization for those of us interested in problems for children from the diaphragm up! We have pediatric and general otolaryngologists, pediatricians of many flavors and subspecialties, plastic surgeons, anesthesiologists, audiologists, speech

pathologists, pediatric nurse practitioners, RNs, PAs and advocates for the manufacturing of safe products with which children might be exposed.

Our stated goals are:

- Assess the science and practice of medicine, surgery, and habilitation as related to diseases and disorders of the ear, nose, and throat of infants and children
- Improve quality of care
- Stimulate and foster research
- Encourage and facilitate scientific exchange, liaison and coordination among professionals engaged in practice/research in audiology, speech-language pathology, otolaryngology-head and neck surgery, pediatrics and related disciplines through an annual meeting and other activities.

The Pre-Conference Symposium will include two sessions on December 3, (see details in the program), which will be of interest to many of our members. The SENTAC program promises to be excellent with a variety of topics in the scientific and poster sessions, panels and breakout lunches. For those of us who regularly attend SENTAC, we appreciate the opportunity to gain new insights into so many areas relevant to our profession. We might easily miss these new ideas when we restrict ourselves to our own specialty of care.

Joan's note will give you more details about the program, which is also posted on the SENTAC website (www.sentac.org). We all owe a special thank you to Marc Steele for taking on the task of providing a web portal for the SENTAC membership.

This portal has given us the advantage that abstract submitters have been doing business on line, which has also made it more efficient for Joan and her committee to do the judging. In addition to the sessions, the informal conversations with our colleagues

during breaks, and with our very important vendor supporters, provide added opportunities to make SENTAC an exciting event. Making new friends and reconnecting with old friends are highlights of all SENTAC meetings.

As SENTAC continues to extend its reach to medical and allied health professionals, several committees have been active in recent months to develop plans to increase attendance by pediatricians, nurses, audiologists, and speech-language pathologists, and to encourage SENTAC members to invite colleagues to join us. All of us know that "each one bring one" typically is the most effective way to increase involvement in any organization. I thank each one of you for your commitment to SENTAC and I too encourage you to bring a colleague who has not yet experienced a SENTAC meeting.

A special thank you goes to Seth Pransky for working with Arthrocare to develop the Arthrocare sponsored lectureship entitled: Enhancing the Care of Children. Arthrocare has endowed this lectureship for the next 4 years. We look forward to this lecture.

Our 2010 meeting will be December 2-5, in Cincinnati, where I will be the Program Chair. I am looking for suggestions from you, and for your involvement in carrying on the tradition of excellence in all aspects of the meeting. Please let me know if you would like to be involved. We can talk in Salt Lake City.

I look forward to seeing you in December!

David

Secretary's Report



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With the end of summer in view, we take the time to reflect upon last year's SENTAC meeting in Boston while looking forward to this year's meeting in Salt Lake City. Last year's meeting showcased the multidisciplinary character of our society. The program consisted of over 45 podium presentations and 35 posters. For the first time in SENTAC history, the poster session was coupled with a reception. The panel discussions were dynamic and led to energetic discussions. The international panel highlighted the similarities and differences in healthcare systems from three continents. Pre-meeting symposia addressing velopharyngeal incompetence and bone-anchored hearing aids drew audiences in excess of 75 attendees. Lunchtime sessions sparked lively discussions and will continue to be a part of the program as

they provide a forum for informal group discussions.

The presentation of the Sylvan Stool award was extremely emotional as a DVD recapping Judith Gravel's professional career and personal life was presented, as Dr. Gravel was unable to attend due to a terminal illness. With the passing of Dr. Gravel, SENTAC and the field of pediatric audiology lost a remarkable individual.

During the business meeting we welcomed 30 new members to SENTAC. We continue to seek diversity of the SENTAC membership with the creation of a long-range strategic planning committee and continuing efforts to recruit local colleagues from the fields of pediatrics, speech pathology, audiology and nursing.

Throughout the year, I have

had the opportunity to respond to e-mail inquiries regarding our society and look forward to continuing to facilitate communication between our members.

See you in Salt Lake!

"In keeping with the SENTAC tradition, the meeting in Salt Lake City will be an outstanding combination of thought provoking presentations and a chance to connect with friends."

Treasurer's Report



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SENTAC remains financially stable thanks largely to the strong support our members continue to demonstrate by timely membership dues payments and careful meeting management by Sheila Seid. We have been fortunate also have loyal corporate supporters who may give less this year but, nonetheless we appreciate the impact of their contributions to support SENTAC's educational mission. Our members and these corporate supporters have voted with their wallets in showing their belief that our unique interdisciplinary forum

for the discussion and dissemination of pediatric ear, nose and throat issues leads to improved healthcare for children, and remains a powerful bridge-builder within and beyond the Society.

It's not too late to encourage membership of your students, trainees, and colleagues. Membership information can be found at www.sentac.org.

Please consider a small contribution - \$50 to \$100 goes a long way - to our Travel Grant Fund. This supports our non-physician members,

without whom our interdisciplinary spirit would not be possible. Your contribution is tax-deductible, and may be mailed to my office or sent by using the check box located on your dues statement.

I hope you are able to enjoy the fall, and we on the Board are looking forward to seeing you in Salt Lake!

Udi

Strategic Planning Committee Report



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At last year's board meeting, the Long Term Strategic Planning Committee was established with a mission to encourage the participation in our organization of non-otolaryngologists: nurses, audiologists, speech language pathologist, primary care providers as well as our international colleagues. The committee on committees put together a diverse group to tackle these issues: Eileen Rall (Chair),

Millicent Collins, Fred Kozak and Roxanne Link.

To move forward on this mission, we first looked back. For our past three meetings we have had the following breakdown for meeting participants:

2006

Total attendees 170: 78 members; 49 non-members; 43 residents / medical students

2007

Total attendees 185: 82 members; 57 non-members; 46 residents / medical students

2008

Total attendees 200: 103 members; 53 non-members; 44 residents / medical students

The breakdown, by degree, for this meeting was: 135 physicians, 26 RNs, 16 AUDs, 8 SLPs, 7 PhDs and 8 others. Three of the conference participants were international (no we are not including our "neighbors from the north" in this count).

In addition, the 2008 meeting hosted presenters from Israel, South America and Canada to discuss the effect of the health care system on delivery of care. In was an informative panel giving conference participants a brief insight to a variety of health care delivery systems.

As our previous years' participation shows, we are already a diverse group, but we are facing the same challenges as other organizations, including the current economic climate, in continuing this diversity. We need to assess the "value" of membership in our organization as well as participation in our annual meeting by our target groups. To do this, early this fall, an electronic survey will be sent to members and previous conference participants. We hope that you will participate in this survey and let us know what you "value" about our organization as well as some ideas to maintain, if not increase, our diversity. Information from this study will be presented to the board at the 2009 meeting and will be available to 2009 conference participants.



Hoodos, Bryce National Park

Impressions of SENTAC

From an old international member...



My first SENTAC scientific meeting was in 1987. Since that conference in Denver, I have been an assiduous visitor.

SENTAC is such a great organization because it brings together several areas of knowledge that converge in Ear, Nose, and Throat Advances in Children. Otorhinolaryngologists, pediatricians, audiologists, speech pathologists, psychologists, and quite a few other specialists contribute every year to the interesting program that always provide the attendees with several new and useful clinical tools to take back home.

One of the aspects that I find most interesting in SENTAC meetings is that although surgical topics are always included, they are not the "pièce de résistance" as in most ENT meetings. Otolaryngology is a surgical medical specialty, but surgery is but a small portion of its extensive field of knowledge. It is not only healthy, but necessary, to tear down the stone pedestal on which the physician, especially the surgeon, is usually situated, presiding over the rest of the

members of multidisciplinary teams that frequently approach ENT disorders.

The best solutions for a patient's complicated complaints are found through a joint discussion by a team, based upon equity, mutual respect, and focusing on the patient's best interest. This is precisely what SENTAC accomplishes so efficiently.

Through my several years of clinical practice, I have had the extreme pleasure of interacting with thousands of patients with craniofacial malformations and their families. In every case, I have found that the participation of several other members of the multidisciplinary team have proven essential for implementing the appropriate treatment in each case. It is impossible to indicate an adequate program of language/speech therapy without the detailed discussion of the case with the speech pathologists. No patient with a craniofacial malformation can be studied without the participation of the clinical geneticist. I could go on and on mentioning several other areas but the bottom line is that there is no doubt that the only efficient method for good diagnosis and treatment is the multidisciplinary approach.

Another case in which the multidisciplinary approach is essential is the patient with profound hearing loss. Whereas functional ear surgery, cochlear implantation or hearing aid fitting are the indicated treatment for each case, the surgeon, the audiologist, the speech pathologist, the psychologist, and some other specialists, should be included in the discussion of the treatment plan. When discussing communication and language development in deaf children, focus has for many years been concentrated on their speech and auditory development, as language development for a long period of time has been equated with speech development. The consequences of this misconception have had, and still have, many negative implications for development in general and of

language development in particular in these children. The synchronized attention to and understanding of events and other emotions, is viewed as fundamental to other developing competences such as language and social cognition. The most significant aspects that a deaf child needs to learn about language are written on the face, body, gestures and the voice of those who talk. We should learn from those who have their own personal experience of being deaf. It is essential that the multidisciplinary team can exchange information with them, not only giving them our views and ideas, regardless of how solid they can appear to us.

When treatment for a deaf child is being discussed, the development of communication and language is as important as social and emotional development.

The thoughts I have allowed myself to present in the former paragraph may be influenced by my over 25-year experience as a physician in my own country, Mexico. However, I have a feeling that these same issues permeate and influence ENT medical practice everywhere.

I know that Audiology, Speech, Psychology, and several other clinical sciences other than Medicine and Surgery, will keep being presented in SENTAC meetings. I will keep making my best effort to attend, not only "to keep the seat warm", but to present the experiences from our public hospital in Mexico City. I am sure I am not the only one sharing this equalitarian point of view. Hence, I know I will never feel isolated during the conference.

See you there...

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SENTAC Memories

from Marc Pellicer...



The first time I heard about SENTAC, I was on the top of an uncovered double deck bus in Oxford (England) chatting with colleagues from the U.S. and Canada about libraries and about Lewis Carroll's *Alice in Wonderland*, under the sun! The conversation was fading when one of the always outstanding Cincinnati fellows began to talk about the forthcoming 2003 SENTAC meeting in New Orleans and of how thrilled she was of attending her favorite meeting of them all. That was in 2002 and I thought I should see by myself what really SENTAC was. I was very busy afterwards but, when in the summer of 2008, I realized SENTAC was going to take place in Boston, I couldn't help presenting an abstract with the great help of my residents...and it was accepted! I didn't know how lucky I had been until I was there meeting Sheila Seid and getting started with the pre-conference symposium on velopharyngeal insufficiency ... all of a sudden that multidisciplinary storm of ideas was getting into my brain and I was learning a hell of a lot of useful things on this always challenging problem. The meeting hadn't even started and it had already been worth coming! And I was already sorry I missed the BAHA workshop!

The warm American hospitality didn't surprise me since I had known it before, but the SENTAC atmosphere was so friendly that I dived into the meeting enjoying every single presentation and the lively discussions that followed. I was very impressed by Prof. Healey's lecture. He spoke with great conviction. Besides I enjoyed very much that genuine American Luncheon Breakout.

My joy was complete when I understood Françoise Denoyelle was there because she was being awarded the award given by Dr. Ruben himself! I have admired that woman since I was a resident and I have tried to follow (hopelessly) her path. And yet when talking to Françoise she is always easy to approach, and she'll try to teach you many interesting tricks, so you are learning the right way to proceed, while you are not even noticing it! Besides she has been the soul of ESPO (with Prof. Noël Garabedian, Martin Bailey, David Albert, John Graham) and a bridge with the new generation of young talents without fear of being outdone by the rookies. So many emotions!

But, wait a minute, this meeting is awesome; now audiologists are presenting very interesting papers with high technical standards. I have to admit that I have a hard time following the discussions nevertheless, and it makes me think that an analysis of hearing health care services currently provided in Europe shows that they are far from sufficient in many respects in most European countries (including Spain where audiology is practiced by people from very different backgrounds). And that even though the improvement of services for the hearing-impaired population in Europe is one of the major goals of the European Federation of Audiology Societies, EFAS, a lot of work needs to be done, like the long-term goal of the implementation of a new profession, here to be called "General Audiologist". This professional is seen as the primary contact person for the hearing impaired

individuals, supported by other professional groups already engaged in the provision of audiological services.

And what a lecture Margaret Bauman gave us on autism! I will remember it for the rest of my life. This meeting has the answers to all the questions I have always had? Astonishing! Then, a multidisciplinary overview on 22q11, so helpful! When you work in a tertiary pediatric hospital in Europe, it's hard sometimes to be understood by your national "adult" colleagues, and the topics in national meetings are miles away from your everyday reality, but boy, not here! SENTAC is unique in its emphasis on encouraging young professionals to pursue the post-graduate expansion of their clinical knowledge and research skills and providing a forum for new health care givers and basic scientists in a way in which knowledge flows with the inevitability of water through any available crease. Everything with the always very practical American approach of not asking questions as speculative as medieval debates about the number of angels that might dance on the head of a pin.

As far as the social program is concerned, walking out and about Harvard, pretending to be a scholar was quite a sensation. And visiting the John F Kennedy Presidential Library brought me memories of my parent's dreams.

Finally, just a word how proud I was of the human quality of all SENTAC members when comforting Judith Gravel through a touching phone call who passed away several days later.

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Battle of the Titans

Who has the best health system in the world?

“As to who has the best health care system? You had to be at the panel session to find out.”

I was asked by Allen Seid to participate in his illustrious panel on the topic of different international health care systems. This is a subject I am not an expert on; however, I am definitely affected by the system in my country. This was also my first meeting of SENTAC, so I was apprehensive as to how the audience would receive the subject.

There was a broad representation of different health care systems and their influence on our practices.

Allen Seid gave an overview of the concept and a glimpse at the U.S. health care system. The topics for discussion were: Description of the system in each country, Access, Cost/Constraints, Evidenced based care, Outcomes and Quality, Positives and Negatives. The main features of the U.S. system were in cost, being the most expensive medical system in the world and yet providing insufficient care for the uninsured. An interesting contradiction, considering that universal medical coverage should be more expensive. It would be difficult to prove that increased costs are a reflection of improved quality of care.

Antonio Ysunza (Phoniatrics Department, Hospital Gea Gonzalez, Mexico City) presented the Mexican model. His main concerns were quality of care in remote and indigent areas including basic health and prevention.

Daniella Carvalho (Pediatric Otolaryngologist at State University of Campinas and Penido Burnier Institute, Brazil) presented the

Brazilian model with similar discrepancies between the different social strata.

Fred Kozak presented the Canadian system which provides universal coverage; however, many problems including long waiting lists for surgery, plague the system.

I presented the Israeli version which is based on the healthcare law passed in 1995 and includes the solidarity principle - payment by ability, services by needs, medical care – a right! All are insured, universal “basket of medical services. Resource distribution – adjusted per capita and progressive health insurance payment. Despite many pitfalls in the system, (low salaries for physicians, for example), when looking at parameters of health, the results are excellent and no one is left out.

It turned out to be a great opportunity to see how the different health care systems work and possibly how to learn from the good and avoid the bad of each system. The panel was easy going and often humorous; the audience participation also impressive.

The panel exemplified how a multi-national approach to subjects of broad interest can enlighten debate. Medicine has no borders and much can be learned from our colleagues around the world.

Due to the multidisciplinary approach of SENTAC, there are a plethora of approaches to learn about in the field of

pediatric ear nose and throat disorders. This makes for a very stimulating meeting.

As to who has the best health care system? You had to be at the panel session to find out.

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Value Judgements in Quality of Life and Cost Effectiveness Studies



One of the most conspicuous — and important — developments in American culture during the 20th century was our society's increasing reliance on technical expertise to solve a wide variety of problems, from predicting the weather to improving personal relationships. Before 1900, rare was the person whose career description ended with "gist" (such as meteorologists, psychologists, criminologists, sociologists ... you get the gist). Now, experts are around the corner of every news broadcast, television talk show, bookseller's stand, and Congressional hearing.

Much of this expertise is invaluable; one would not want to go back to predicting the landfall of hurricanes based on the flight of birds. Indeed, the remarkable accomplishments of modern medical practice are compelling testimony to what technical expertise can offer. But like all great strengths, the technical approach to problem solving creates its own set of problems, which need to be identified, understood, and managed.

Over the past 30 or so years, two new realms of technical expertise have emerged — the measurement of quality of life (QOL), and the conduct of cost-

effectiveness analysis (CEA) — and are increasingly used to evaluate medical treatments and guide health care policy. For these particular forms of technical analysis, the methods and, thus, the results depend upon core assumptions that are based in value judgments. Even though these value judgments are subsequently manipulated and molded into esoteric concepts (such as quality adjusted life years, or QALYs) and used in complicated ways (such as league tables that compare the cost per QALY of different treatments), the basic value judgments themselves are not esoteric, and should be understood and debated by the folks whose lives and healthcare will be affected by the analyses.

Let's look at 2 examples and then consider an ironic twist. First, there is value judgment that has to be made regarding who to ask when gathering data about quality of life for people with different medical conditions. Do we ask people who actually have the condition (believing that they know the most about what life is like with the condition)? Or do we ask people who do not have the condition (believing that these unaffected people will not be biased, pro or con, about the quality of life of living with the condition)? Or do we ask a random sample of the population, so that the perspective of society is more accurately recorded (but aware that this will mostly be the perspective of unaffected people, who may be quite ill-informed about what life with the condition is actually like)? Which group to pick is a judgment call: are we more concerned with self-representation and the knowledge that comes with lived experience; or are we more concerned with preventing self-interest or personal bias from entering into the data; or are we most concerned with attempting to achieve an ideal "societal perspective" when performing analyses that can have society-wide implications? Experts can, and do, argue about these underlying values — but every one of us should be aware that studies reporting QOL results can differ fundamentally about which of these value judgments guided their methods and (often radically) shaped their results, and decide for ourselves which values framework we think is more appropriate.

The second example is, well, a bit technical, but VERY important, especially for children. Suppose we have 2 surgical treatments for serious medical conditions, one of which is used for young children (with a life expectancy of 40 years) and the other for old adults (who can expect to live another 10 years). Both treatments cost exactly the same amount and improve the QOL of either the young child or the old adult, but more so for the adult, from a score of 0.8 to 0.9 (with perfect health being a score of 1.0), than for the children, whose scores rise from 0.8 to 0.83. Saying this somewhat differently, the adults QOL rises 0.1 points, while the children's rises a third of that amount, 0.03. Okay, so now that we know all this, which treatment yields greater benefit? Well, if our outlook is short-term, for just 1 year, then the adult treatment is more beneficial. If our outlook is long-term, then the child treatment appears to be more beneficial, as we multiply the rise in QOL for each treatment by the life expectancies of the children ($0.03 \times 40 = 1.2$) and the adults ($0.1 \times 10 = 1$). But this is not how most cost effectiveness studies do the math. Instead, the benefit of the treatment is discounted over time, usually at 3%. Using this approach, the adult treatment pulls ahead as more beneficial over the expected lifespan (with a total net QOL benefit, after time discounting, of 0.7 for the children compared to 0.88 for the adults).

Did everyone follow that? Essentially, if we place greater value on short-term results, either by limiting the analysis to only 1 year or by factoring in a discount rate, then our (I believe quite common) conception that children have a greater claim to health care because they have the rest of their (long-term) lives to live is thrown out the window. Essentially, we devalue the future.

Perhaps we should; perhaps we shouldn't. Perhaps the discount rate should be 3%; perhaps less or more. The point is that we need to understand, in general terms, how these technical calculations work, and debate the value judgments lying at their core.

Now for the promised ironic twist. Suppose we are advocates for medical treatment for a particular pediatric condition, because we are advocates for the children with this condition. When confronted with the first example, regarding who should be asked for QOL data, we may be inclined to say that only people with the condition, or intimately knowledgeable about what life is like for children with the condition (such as experienced parents), should be asked. In general, when this group of people is asked, they rate the QOL higher than when people without the condition or who know little about the condition are asked. If a treatment comes along and improves the QOL, the net benefit from the treatment may well be rated as larger among people who do not have the condition than among people who are intimately familiar with life with the condition. Now if this data were to be used in a cost-effectiveness analysis, rather ironically, the stronger case for the net cost-benefit of the treatment would be based on the data from the persons unaffected by the condition. While this certainly would not always be the case, we need to be alert to how QOL measurements are used not just to paint a picture of how children are doing, but also to decide between different treatment options.

One role that medical ethics has in our society is to point out as clearly as possible the value judgments that so greatly influence our technical approach to problem-solving, and foster debate. To that end, you might want to discuss some of the questions raised here with your colleagues or even (if they want) families and patients. We all need to understand these issues, as they will increasingly dominate the way the healthcare decisions are made.

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Resilience: The Important Role of Parents



Cindy has asked me to contribute to this newsletter with some thoughts about the resilience we have seen in children. As we have worked together providing neurodevelopmental and speech and language follow-up for multiple high-risk populations, some children just stand out as “stars”. I will share with you here some of what is known about resilience in children and some of my recent work providing parenting interventions.

We have all seen it. Those children and families who, despite all that they have gone through – surgeries, bad news, NICU stays, disabilities, and family tragedies – make it through and come to see us in our programs as successes. What is it that helps some children do well while others remain more vulnerable to the biological and environmental stress that they face?

Researchers have devoted careers to answer these questions. Clinicians have tried to capture those characteristics of strength and create therapy programs to empower the more vulnerable or at-risk families. Communities and cities have tried to change the ways whole systems work in order to support resiliency. Look at the work of Geoffrey Canada and the Harlem Children's Zone. This is an innovative and unique community-based organization that offers education, social service, and community-building programs to children and families. Services range from baby college, preschool, and schools for adult services all in a concentrated geographical area (www.hcz.org). Some entrepreneurs are boldly selling products that will promote resilience. For example, there are

“Essentially, we devalue the future.”

websites that are selling the music of Mozart with promises of increases in IQ points based on unfounded evidence of increased brain development in children under age 3 when they listen.¹

What is resilience? Resilience is the positive adaptation in the context of significant adversity.² There are many factors that contribute to resilience. However, the underlying processes that create the protection still need more study. One factor contributing to resilience is the lack of risk factors that create vulnerability. Other factors appear to be protective.

Is it genetics? In a recent study, we found that children with congenital heart disease who require surgery as infants may be more vulnerable to neurologic problems if they have a particular variety of a gene. Researchers from the Cardiac Center and other divisions of The Children's Hospital of Philadelphia found that Apolipoprotein-E (*APOE*) plays a role as a susceptibility gene. Those children with the *APOE* ε2 allele were significantly more likely to have worse neurodevelopmental outcomes at age one compared to children who also underwent surgery but did not have *APOE* ε2. *APOE* ε2 occurs in approximately 8% of the population. At age 4 years, the *APOE* ε2 allele was significantly associated with worse problems in somatic complaints, pervasive developmental problems, and internalizing problems. As *APOE* ε4 was associated with better outcomes in these areas, it appears to be a factor supporting resilience.

But, it is more than genetics that can guide a child safely into resilience. One factor often mentioned by researchers is the presence of a close bond with a parent or an important adult in a child's life. While a strong parent-child relationship is an expectation in our culture, as families' lives become more stressful, it can be hard to maintain or may not even be present for a child. Families may be faced with numerous challenges due to the illness or medical condition of their child. Poverty has been found to create a high level of parental stress. A parent's own mental illness, such as depression,

can interfere with a child's resilience. Resilience research has suggested many components of a relationship that might be part of the underlying process. One factor is consistency – knowing that a person will always be there and be a primary source of social support. A parent is often a champion for a child. A parent often models a positive attitude and advocacy. As a result, optimism, calmness, unquestioning love, and acceptance are then present for the child. Factors in the parent-child relationship that promote attributes in a child such as strong self-esteem and an outgoing and positive social attitude are also protective to a child.

There are a number of evidenced-based programs for parents whose principles mimic the concepts of what supports resilience. Incredible Years (IY), Parent Child Interaction Therapy (PCIT) and Triple P (Positive Parenting Program) are just some that are in use. The primary audience for these programs is families who have children with behavior challenges. They each start with steps to strengthen the parent-child relationship. Typically, they begin by teaching parents to use praise, attention, and narration. They encourage having periods of child-lead activity. They urge parents to stay away from criticism and negative commands in favor of comments that build and support self-esteem. They teach parents to assume a style of calmness, clarity, and positive comments. Less "no" saying and more "redirection" are recommended. Praise is given for compliance. These parenting programs offer parents techniques to nurture resilience in children and improve their behavior. These parenting initiatives use models of active learning such as role playing, live coaching, active discussion and, in some cases, peer support. The efficacy of IY and PCIT has been supported by research across multiple settings and populations

So, as we approach each child and family in our work, we know that some children will be more vulnerable than others. We know that there are many factors that are out of our control to change. But, by recognizing the important role of the

parent in each child's life and its potential impact on resilience, hope is offered.

1. Bruer John T. *The Myth of the First Three Years* (Free Press, 1999).
2. Luthar S, Cicchetti D, Becker B. The construct of resilience: A critical evaluation and guidelines for future work. *Child Development* 2000;71(3):543-562.

IY (www.incredibleyears.com)

PCIT (www.pcit.phhp.ufl.edu)
Triple P (www.triplep.net)

Marsha Gerdes, PhD

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"But, by recognizing the important role of the parent in each child's life and its potential impact on resilience, hope is offered."

Welcome New Members!

2008 Award Recipients

Judith S. Gravel, PhD

The *Sylvan E. Stool Award* for her outstanding lifetime contributions to teaching and service in the field of ear, nose and throat advances in children.

Harlan Muntz, MD

The *Steven Gray Award* for his outstanding lifetime humanitarian contributions in the field of ear, nose and throat advances in children.

Francoise Denoyelle, MD

The *Robert Ruben Award* for her outstanding lifetime contributions to scientific advancement in the field of ear, nose and throat advances in children.

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Future Meetings

SENTAC

December 2-5, 2010
Cincinnati, OH

ACPA

March 16-29, 2010
Fort Worth, TX

ASPO

April 30 - May 2, 2010
Las Vegas, NV

The Voice Foundation

June 2-6, 2010
Philadelphia, PA

AAO-HNS

September 26-29, 2010
Boston, MA

ASHA

November 18-20, 2010
Philadelphia, PA

In Memoriam Judy S. Gravel, PhD



Dr. Judith S. Gravel passed away on December 31, 2008, at Mt. Sinai Medical Center in New York after a valiant battle with ovarian cancer. Throughout her illness, she continued to serve as the Director of the Center for Childhood Communication at The Children's Hospital of Philadelphia (CHOP) where she elevated the service, education and research mission of the center through her strong leadership and mentoring.

An internationally renowned pediatric audiologist, Judy held the William P. Potsic Endowed Chair in Pediatric Otolaryngology and Childhood Communication at CHOP. After earning her bachelor's and master's degrees at the University of Massachusetts at Amherst, Judy practiced clinically in the Washington, DC area at Gallaudet University and the Fairfax County Public Schools before earning her Ph.D. at Vanderbilt University.

Judy held faculty appointments at Columbia University, Albert Einstein College of Medicine, Vanderbilt University, and the University of Pennsylvania. A Fulbright Senior Specialist in Global/Public Health, Judy served on or chaired more than 60 committees, panels, task forces, and review

teams on behalf of the National Institute on Deafness and Other Communication Disorders, The Centers for Disease Control and Prevention, U.S. Public Health Service, Commission of the European Communities Directorate, National Early Hearing Detection and Intervention Technical Assistance Advisory Group, International Working Group on Childhood Hearing, the Pennsylvania Department of Health, the American Speech-Language-Hearing Association and the American Academy of Audiology. Her prolific research activities resulted in the publication of more than 100 peer-reviewed scientific and lay articles and 35 book chapters in the area of pediatric audiology. Her groundbreaking work on early detection of hearing loss, early intervention and otitis media greatly advanced the specialty of Pediatric Audiology. However, her focus and greatest energy were consistently devoted to applying research findings to clinical practice to improve the lives of children with hearing loss, as evidenced by her love of teaching and clinical care.

While leading the Center for Childhood Communication (CCC), Judy was awarded the Honors of the Association of the American Speech-Language-Hearing Association, The Sylvan Stool Award for Lifetime achievement in Teaching and Service from the Society for Ear Nose and Throat Advances in Children (SENTAC), The Antonia Brancia Maxon Award for Early Hearing Detection and Intervention Excellence at the National EHDI Conference, and the Distinguished Achievement Award from the American Academy of Audiology.

The daughter of Muriel and the late Leonard Gravel of West Springfield, MA, Judy is survived by her husband, Bruce Taylor of Wilton, CT, her sister Janet Angelico (Joel) of Foxboro, MA; Bruce's children Julie (Joshua) Taylor Hall of Charleston, SC and Jay (Adrian LeMaster) Taylor of Franklin, TN; six grandchildren; and six nieces and nephews.

Those who knew Judy respected her wisdom and humility. She held the highest standards of professionalism and personal integrity. She was admired and loved by everyone who had the good fortune to know her. Most importantly, she will be dearly missed.

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The **Society for Ear, Nose and Throat Advances in Children, Inc.**, is a non-profit interdisciplinary professional organization founded in 1973. Its members are otolaryngologists, pediatricians, surgeons, pediatric otolaryngologists, speech pathologists, audiologists, nurses, and basic scientists - all of whom are interested in enhancing the care of children with acquired or congenital disorders of the ear, nose, and throat.



Salt Lake City Skyline