

# PERSPECTIVES

*in genetic counseling*

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**national society  
of genetic  
counselors, inc.**



*The leading voice, authority and advocate  
for the genetic counseling profession.*

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NSGC acknowledges Women's Health Care Services for a generous grant to support this newsletter.

Women's Health Care Services, providers of late abortion care for fetal anomalies, George R. Tiller, MD, Medical Director. Meet Dr. Tiller's staff at a Presidential Reception at our Annual Education Conference in Denver, generously sponsored by WHCS.

## PROFESSIONAL STATUS SURVEY RETROSPECTIVE

NSGC's first professional status survey in 1980 was mailed to 238 full members with a response rate of 150 (63%). In 1998, this nearly bi-annual study boasted a mailing to 1208 full members with a 816 (68%) response rate. While salary is the most sought after information derived from the survey, an interesting trend in diversity of career opportunities has emerged. No longer is the choice simply prenatal or pediatric genetic counseling. Today, cancer risk counseling and other adult-onset disorders have demanded the expansion of genetic counseling roles. Several random comparisons are listed below.

	1980	1990	1998
Employed in university medical center. . . . .	60%	52%	47%
Responsibilities include adult onset disorders . . . . .	N/A	N/A	31%
Hold faculty appointment . . . . .	10%	19%	23%
Board certified . . . . .	58%	64%	73%
Median income, new graduates . . . . .	\$16,000	\$30,236	\$36,000
Median income, 5 years experience . . . . .	\$18,700	\$30,425	\$42,500
Minimum reported income . . . . .	\$12,000	\$26,125	\$18,000
Maximum reported income . . . . .	\$32,000	\$47,875	\$80,000

For a full report on the 1998 Professional Status Survey.

*See and save* enclosed 8-page document, *Professional Status Survey 1998*.

## Point Counterpoint

### BOARD EXAMS FOR GRADUATING STUDENTS

*Regardless of when the Board exam is taken, studying requires long-term planning and persistence. This difficult decision ultimately must be made by the individuals based on their own strengths and styles.*

#### ...On the Pro Side

Allison Gregory, MS

The decision to take the American Board of Genetic Counseling (ABGC) examination directly after graduation is so difficult that some students wish they were not faced with the option. Clearly, the final months of graduate training are rigorous. Prior to graduation, many students will finish a thesis or project and/or take

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#### ...On the Con Side

Lisa Steinberg, MS

Preparing for the certification exam is a difficult task, requiring several months of intensive review. Therefore, I believe it is not appropriate for genetic counseling students to devote a significant portion of their time and energy preparing during their second year of

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## SURVIVAL SKILLS FOR GENETIC COUNSELORS: WHAT YOU DIDN'T LEARN ...

### TAKING CHARGE OF YOUR TIME!

*Liz Stierman, MS*

They ought to call us “frenetic counselors.” Stretched in many directions, most of us are perpetually busy. Is it a struggle just to stay caught up? Do you find yourself working late? Waking up at 2:00 am worrying about that stack of charts on your desk? Blaming yourself, thinking, “If I were just more efficient... .”

### FILL IT TO THE RIM

A time management expert speaking to a group of business students used this powerful illustration to make a point. He placed a wide-mouthed mason jar in front of him. He then carefully placed a dozen fist-sized rocks, one at a time, into the jar. When it was filled to the top he asked, “Is this jar full?”

“Yes,” replied the class. “Oh, really?” he said, and took a bucket of gravel from under the table. He poured in some gravel and shook the jar, allowing the smaller stones to work themselves into the spaces between the big rocks. Smiling, he asked once more, “Is the jar full?”

“Probably not!” The speaker then filled the spaces left between the rocks and the gravel with sand. Once more he asked, “Is this jar full?” “No!” the class shouted. “Good!” He poured water from a pitcher until the jar was truly filled to the brim.

What is the point of this demonstration? No matter how full your

schedule is, if you try really hard, you can always fit some more things into it? The speaker sagely believes that if you don't put the big rocks in first, you'll never get them in at all.

### KEEPING SIGHT OF PRIORITIES

Isn't this how many of us try to manage our time — by cramming in as much as we possibly can? No wonder it seems like the urgent

### LEARNING ABOUT LIFE FROM MY PATIENTS

*Katherine Hunt, MS*

My best days counseling are often the ones that are long, chaotic and stressful. The patients arrive one hour late, backing up the entire day. The doctor disappears when the patient is ready for her ultrasound and my pager goes off at least twice during a very difficult session. After this type of day in the clinic, I am surprised at the sense of satisfaction I often feel. I walk back to my office lost in my thoughts on how much about life and myself I've learned from the families I've met that day. Ironical — is it not the genetic counselor's role to enlighten and educate? At which point during the session did I lose control of my agenda?

That's my problem right there: *control*. I like to have everything in its place and when things become untidy, I simply straighten it the way I want. Theoretically, this is a productive way to live. But is this realistic? When a patient arrives several hours late, and the waiting room is filled with worried, anxious faces, how do I choose which patient to see first? How can I organize a conversation with a crying teenager about her son who will be born with gastroschisis? What is tidy about having a discussion with a couple preparing for their impending early induction of a fetus diagnosed with Down syndrome? There simply is no structure to pain and it is not possible to organize the healing process for our patients.

These confusing clinics serve as a reality check for me, a reminder of the purpose of genetic counseling. My attempt at creating order is likely how I cope with the fact that pain and loss have the ability to seep into anyone's life. But it's not my job to prevent them from feeling this pain or experiencing the sadness and make it better each time. As I learn not to focus on the status of the order around me, it becomes evident how important it is to sit quietly and listen to our patients' grief, confusion and loss. This takes patience. As I struggle to understand what they must be feeling, I search for words to comfort and ease their fears. I remind myself that there always can't be an explanation and that that's not really why they come to us. It's often enough to let go, grieve with them and listen. The genetic counseling session becomes a process rather than an end point. When the dialogue between the patient and the counselor is successful, both participants will hopefully walk away enlightened with a better understanding of themselves and the knowledge that ultimately, through the chaos, comes peace. ♦

## MEET YOUR 1998/99 BOARD

### ...IN GRAD SCHOOL

things always take precedence while the projects we'd love to do — writing that article for the *Journal of Genetic Counseling*, for example — seem to fall by the wayside. Here's what experts from the "real world" teach us about time management:

- **ASSESS** how you spend your time by keeping a log. Try 15 or 30 minute blocks. Are phone calls or other interruptions whittling away your day?
- **IDENTIFY** what you want to accomplish, listing your objectives and ranking them.
- **CALCULATE** realistically how much time you need for each task.
- **KEEP** a written "To-Do" list. Include everything you do or want to do on your list — don't forget exercise! Highlight the items with greatest priority.
- **RESIST** temptation to do the "easy" things first before tackling higher priority tasks. Clear off your desk so you won't be distracted by other work — focus on what is most important, not what is most visible!
- **CONTROL** distractions. Arrange to return phone calls at a set time so you can concentrate on other work.
- **UPDATE** your list before going home each night. Not only will this help you plan tomorrow, it's a good way to control your after-hours anxiety about unfinished work.

The "To-Do" list has some added benefits. You will realize how much you do get done. Show it to your boss! It may help justify that extra assistance you need! ♦

*Submit your Professional Survival Skills experiences to Katherine Hunt, MS, <Katherine\_hunt@somaf.unm.edu>*

We are pleased to announce the following elected, appointed and returning members who will serve as your Board in the coming year.

#### Officers/Executive Committee

Debra Lochner Doyle, MS (3)*	President
Wendy Uhlmann, MS (2)	President-Elect
Stefanie Uhrich, MS (0)	Secretary
Kristine Courtney, MS (1)	Treasurer
Lisa Mullineaux, MS, MBA ( <i>ex officio</i> ) (0)	Treasurer-Elect
Maureen E. Smith, MS (4)	Past President I
Ann Happ Boldt, MS (5)	Past President II

#### Committee Chairs

Barbara J. Pettersen, MS (1)	Education
Lisa Amacker North, MS (3)	Finance
Robin Bennett, MS (1)	Genetic Services
Kristin Baker Niendorf, MS (0)	Membership
Kathy Schneider, MPH (3)	Professional Issues
Anne Spencer, MS (0)	Social Issues
Janice Berliner, MS (3)	Editor, <i>Perspectives</i>

#### Regional Representatives

Kathryn Spitzer Kim, MS (1)	Region I
Karen Johnson, MS (0)	Region II
Denise Tilley, MS (1)	Region III
Leslie Cohen, MS (0)	Region IV
Katie Leonard, MS (1)	Region V
Steven Keiles, MS (0)	Region VI

*\*(n) represents previous years served on Board before this term*

Thanks to the Nominating Committee for a job well done: Ann Boldt, Chair; Wendy McKinnon (I); Merry Ferre (II); Beth Buehler (III); Ann Greb (IV); Jill Sawyer (V) and Jana Klein (VI). ♦

## CELEBRATE OURSELVES!

Congratulations to the following members who have been appointed, awarded or elected!

- **Liane Abrams** • Jarrett Cole Award for Excellence, Fragile X Society
- **Debra Collins** • Elected to Board of Directors, American Society of Human Genetics
- **Betsy Gettig** • CDC's Career Development Award in the newly established Office of Genetics and Disease Prevention. She will return to direct the University of Pittsburgh Genetic Counseling Program in one or two years.
- **Robin E. Grubs** • Named Interim Director, University of

Pittsburgh Genetic Counseling Training Program

- **Bonnie LeRoy and Susan Schmerler** • Elected to Board of Directors, American Board of Genetic Counseling
- **Caroline Lieber** • Appointed Director, Sarah Lawrence College Genetic Counseling Training Program
- **Colleen McGillis Dougherty** • Appointed Director, Northwestern University Genetic Counseling Training Program. ♦

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# GLOBAL PERSPECTIVE: GENETIC COUNSELLING IN AUSTRALIA

Anne Timko Evans, MS

Australian clinical genetics programs have more similarities than differences with their North American and European “mates.” Genetic counsellors working in genetic service programs in Australia and New Zealand (aka Australasia) are mostly based in pediatric or obstetrical departments of large public hospitals. Outreach services, many coordinated by local genetic counselors, exist in a limited number of smaller health centers in both urban and remote areas. So far, only one counsellor has successfully entered the “private” or commercial sector, being employed by a private IVF facility.

## SISTER ORGANIZATIONS

The Australasian Society of Genetic Counsellors (ASGC) was initiated in 1992 and two years later was formally recognized as a special interest group of the umbrella organization called the Human Genetics Society of Australasia (HGSA). (What fun

keeping these acronyms separate from the American ones, which happen to use the same letters in a different order!) HGSA, formed in 1977, has similar roles to those of the American Society of Human Genetics and American Board of Medical Genetics. ASGC, with its approximately 80 Full and 30 Associate members, meets twice a year at a rotating location. One meeting is held in the fall, and is comprised of a two day educational program, and one is in the spring, comprised of a half-day program held in conjunction with the four day HGSA scientific meeting.

## CERTIFICATION

HGSA's Board of Censors grants certifications in genetic counselling, medical genetics and lab specialties.

The genetic counselling certification process has two parts, based not on an examination, but rather course study and work experience. Part one consists of academic study in HGSA-approved courses. Formalized graduate programs in genetic counselling have recently been added to a limited list of university-level courses approved for part-one course work. The first of the four current graduate programs began in 1995. I serve as lecturer and student coordinator. Three programs are in state capitals and the fourth is a “distance learning” (correspondence) course. Three of these programs offer diplomas in genetic counselling after a one year full-time or two year part-time course of study, granting the masters degree after an additional research year. Prior to these programs, much of the part-one course work was painstakingly undertaken by employed or prospective genetic counsellors —

mostly from nursing or social work fields — one or two courses at a time.

Part two of the certification process consists of demonstrating clinical competency — HGSA's Board of Censors acceptance of logbooks consisting of 50 “short” and 20 “long” (annotated) cases, based on a minimum of two years experience in the field.

The first full genetic counselling certifications were granted in 1991. There are currently 13 fully certified genetic counsellors in Australasia. About half of Australasia's working counsellors have completed part one, about 40% are working on part two and 10% are not involved in this process.



## PROSPECTING AN ADVENTURE ABROAD

Some North American genetic counsellors and students have E-mailed me asking about job prospects in Australia. Unfortunately for them, the tide has changed since the onset of the formal training programs. With homegrown counsellors, there are now few reasons for employers to seek “migrant” workers. The strict employment and immigration laws make it extremely difficult to obtain a position, unless someone is here on another type of visa (spousal, dual citizenship, etc.).

When Australian candidates are found (even if less qualified), they have first choice. With the training programs graduating about 10 counsellors a year now, limited funds for established programs to add positions and minimal growth of the field into the private/commercial sector, a shift in this trend is unlikely to happen in the near future. ♦

## GC TRAINING PROGRAM INTRODUCED IN AUSTRALIA

Melbourne University, in conjunction with the Murdoch Institute, has announced a newly-initiated Masters in Health Sciences (Genetic Counselling).

The program is a one year full-time or two years part-time course. Margaret Sahhar, a long-standing NSGC member, will serve as Convenor.



## TAKING BOARDS: THE CON SIDE, *from p. 1*

graduate training.

Students are attending clinical rotations, arguably the most important part of their training and should be the highest priority. Students should take full advantage of this opportunity to learn under the supervision of experienced genetic counselors without being preoccupied by the boards.

Many students are also completing research projects and coursework while searching for a job. These activities may suffer as a result of the intense preparation required for the board exam. The risk of having to retake the exam because of poor preparation must also be considered.

Others may argue that students recently completing their training may be in a better position to sit for the boards because their knowledge is fresh, and they have not yet specialized. However, these

arguments are contrary to the purpose of the board exams, intended to test comprehensive knowledge of genetics and its application in a clinical setting. It is most often while working and integrating principles obtained in training into actual practice that it all "comes together." The benefit of at least some professional clinical experience prior to taking the boards is great.

In addition, many general concepts covered on the exam, including pedigree and risk assessment, diagnostic techniques, legal and ethical issues and counseling principles, apply to nearly all specialties. It is reasonable to expect that all genetic counselors, regardless of certification, specialization or number of years in the field, will maintain a general knowledge of these concepts. ♦

## TAKING BOARDS: THE PRO SIDE, *from p. 1*

a cumulative examination. Coursework and final exams must also be completed. Initially, this appears to be an inopportune time to study and sit for the board exam. However, upon further consideration, many students may find that taking boards immediately after graduation is optimal.

New graduates have just completed up to two years of coursework and have, perhaps, the broadest knowledge base of genetics and specific skills integral to genetic counseling. Still generalists, they may be better prepared for the variety of topics covered by the general and counseling exams than at any time in the future. Once working in the field, most genetic counselors primarily specialize in one area.

Several of the training programs now require students to complete a cumulative test, designed to mimic the board exams. Thus, when sitting for the "real" exam, new graduates may be more comfortable performing in a timed, stressful, test-taking environment. Unlike counselors working in the field, new graduates, if not working, have more flexibility and time in their schedules for studying. Those who have just begun to work may be able to negotiate time for study during the workday.

Finally, some students have questioned whether being board certified will strengthen their applications for genetic counseling positions. If two applicants appear otherwise equal, board certification will likely serve as an advantage. In addition, it may provide bargaining power during salary negotiations or be an accomplishment for which employees receive a monetary bonus. ♦

## BOARD REVIEW COURSE; STUDY GUIDE

**NSGC** and the University of Pittsburgh will again offer a comprehensive review of medical genetics and genetic counseling for persons studying for the 1999 American Board of Genetic Counseling (ABGC) or American Board of Medical Genetics (ABMG) Board exams. The course may also be taken by genetics or other professionals wishing to review or update their knowledge in these areas.

The course dates have been scheduled on both the East and West Coasts to accommodate

April 30 - May 2      Pittsburgh PA

May 14 - 16      Oakland CA

The courses will have identical content and faculty.

☛ Brochures will be mailed in early January to all persons taking ABGC or ABMG Boards in 1999. If you requested an advance copy of the registration and information brochure and have not received it by October 15, please fax or E-mail your request to NSGC c/o  
Fax: 610-872-1192 or [nsgc@aol.com](mailto:nsgc@aol.com)

## STUDY GUIDE

*Medical Genetics: Overview and Study Guide*, 3rd ed., is a comprehensive, 205-page, 12-chapter manual. This indexed, referenced study guide covers the topics needed to study for the general and genetic counseling boards. Study questions are included.

☛ For information: Janice Berliner, ©908-771-5582; [jberliner@aol.com](mailto:jberliner@aol.com). ♦



## On the Road

with Lavanya Misra, MS  
& Aditya Pai, MS

# GENETIC COUNSELING IN INDIA: CHALLENGES, BARRIERS AND PROGRESS

**While** genetic services are rapidly expanding in North America and Europe, progress in human genetics is moving more slowly in developing countries such as India. Recently, the Indian government took bold steps to move into the era of genetic screening by offering testing for a number of genetic disorders like B-thalassemia, sickle cell disease, Duchenne muscular dystrophy and Fragile X syndrome. Diagnostic testing is also in preparation for conditions like congenital adrenal hyperplasia, myotonic dystrophy, retinoblastoma and mitochondrial disorders. While the above measures may be viewed with optimism, the role of genetics and genetic counseling in India brings with it complex issues, including sex selection, cultural diversity, language barriers, poverty and limited availability.

## CHALLENGES

There are no formally trained genetic counselors in India, and physicians are responsible for the majority of the counseling. Therefore, thorough and adequate informed consent prior to genetic screening is limited. Hence, providing genetic counseling presents a major challenge. India is nearly  $\frac{1}{3}$  the size of the United States with a population of over 930 million. It is a nation that has many different religions, customs and languages. There are as many as 200 unique languages and dialects. Hindi, the predominant language, is spoken by

nearly 30% of the population; English is spoken by only 3%. However, English is the primary language of communication and instruction in most city schools and universities as well as in most governmental institutions.

## BARRIERS TO SERVICES

Most Indian families respect physicians and dutifully follow their advice. However, in return they expect a diagnosis and a cure. This is contrary to the principles of genetic counseling in the United States, which rely on non-directive counseling and patient autonomy. Also, abortion is accepted in Indian society, and in some cases may even be expected, as the emotional, financial and societal burden of raising a child with a birth defect can be harsh. This is in part due to a lack of medical resources and appropriate intervention centers for families with children with genetic disorders, as well as society's perception of disabilities. A family facing the prospect of raising a child with a genetic condition may face tremendous social stigma. With limited resources available, parents carrying a child with a genetic disorder may have very few alternatives and face difficult dilemmas.

Amongst women of marriageable age, carrier testing can lead to stigmatization if they are found to carry an altered gene. Non-traditional measures have been known to work for those already identified as carriers. At one center where carrier testing is being offered for sickle cell anemia, the director advises unmarried carriers that the sickle cell is a god who does not want to marry another god. The approach appears to work

because of the strong religious beliefs engrained in many Indians.

## INTRODUCING FORMAL TRAINING

As genetic counselors from India, we recognize that the impact and scope of genetic testing in India is tremendous. We believe that public education is the key to increasing the awareness of genetic testing and its impact on individuals. Through contacts with family and friends who have remained in India, and regular meetings with university officials, we are attempting to help set up a Masters program in genetic counseling for students in India similar to the programs accredited by the ABGC.

Such a program would:

- Promote appropriate education
- Create a well-planned infrastructure of genetic laboratories and services
- Address the question, who is the genetic testing and counseling for, and who will pay for it?
- Establish a strong program that will produce genetic counselors who will be able to work with geneticists and help provide culturally sensitive counseling to the community.
- Increase awareness and educate the health care community.

Lectures on genetic counseling have been given to undergraduate students in a prestigious institution in Bombay, and great interest has been generated. The next step is to organize a genetics curriculum specific to and appropriate for the needs of the Indian population.

We hope to continue this endeavor with support from NSGC's international subcommittee. ❖

## DUTY TO WARN: CONTACTING THIRD PARTIES

*This article is the last in a three-part informational series about an emerging policy and legal issue that may affect clinical genetic counseling practice. While the logistical concerns of contacting at-risk third parties are beyond the scope of this paper, the principles involved need to be considered. The information included in this series of articles is intended to provide background information and is not to be construed as legal advice. The Social Issues committee sincerely thanks all those members who sent comments and supplemental information.*

Chantelle Wolpert, MBA, PA-C

In genetic counseling, medical genetic risks may be identified that extend beyond patients to their biological family members. Some of these cases may challenge genetic counselors and other genetic health professionals about whether their patients' rights to privacy are not as important as the duty to warn. If the patient agrees to contact at-risk relatives, how should this be done? Should genetic counselors be involved? Are genetic counselors well-equipped to deal with these dilemmas involving individuals' privacy and their right *not* to know?

### WHEN THE PATIENT ACCEPTS...

The genetics department may provide a general letter which:

- informs family members who may unknowingly be at-risk for developing or passing on a genetic disorder
- provides detailed information about how to contact a genetic counselor or other appropriate health care professionals.

Such a letter could be mailed to all family members identified by the patients. A copy of the letter and any returned letters should be kept on file, providing proof that there was a good faith attempt to contact relatives potentially at-risk.

### WHEN THE PATIENT DECLINES...

What about patients who do not wish to contact at-risk family members? There are many reasons

for individuals not to want to disclose information about carrying a disease-causing gene.

While it is not possible to imagine every scenario, the genetic counselor can consider what actions, if any, might be taken if a patient refuses to contact a relative who may be at-risk for developing or transmitting a genetic condition. In most instances, the genetic counselor's primary obligation is to the patient. Confidentiality is fundamental.

Furthermore, the National Society of Genetic Counselors' Code of Ethics (Section II, Item 5) states, "Maintain as confidential any information received from clients, unless released by the client." Furthermore, breaching patient confidentiality, besides being unethical, could result in a lawsuit

### RECONSIDERING VIEWPOINT...

These cases may cause counselors to reconsider their views and how they act when exercising the duty to warn third parties. Some situations may arise when the genetic health care team must work together to come to a decision that is congruent with their moral, ethical and any prevailing legal standards. There may be some cases in which a genetics team decides that the patients' rights to privacy are not as important as the duty to warn. They may reason that preventing potential harm to other family members and/or future generations prevails.

### BEYOND THE PATIENT...

It may be possible to anticipate some of these dilemmas and design general policies or guidelines for how to handle them. Ultimately, however, case law decisions may determine how and when the duty to warn third parties should be applied in a medical genetic setting. Genetic counselors and other genetic health care providers must think about how and when this duty should be applied in clinical genetic counseling practice. For these reasons, this policy issue needs further discussion within our profession.

### WHERE TO GO FROM HERE...

This series neither advocates nor discourages genetic counselors to apply the duty to warn third parties. Instead it provides an overview of when a duty to warn may exist in genetic counseling practice and provides some practical guidance for handling such situations.

Additional areas of research beyond this summary include whether genetic counselors should:

- be involved in the process of contacting the third parties;
- coordinate the logistics of this responsibility in medical genetic settings; and
- adopt clinical practice guidelines.

The challenge is ours to face. ❖

# WHAT'S ON THE WEB?

Shelly Cummings, MS

Here are a few useful web sites that various members have contributed. If you have found other relevant sites, please post them on the listserv or forward them to me by E-mail. We can all benefit from each other!

- EUROPEAN DIRECTORY OF DNA DIAGNOSTIC LABORATORIES  
This valuable site is similar to Helix. Search by either the specific syndrome of interest or by the McKusick number.  
[www.eddnl.com](http://www.eddnl.com)
- AMERICAN SOCIETY OF CLINICAL ONCOLOGY (ASCO)  
Professionals with specific expertise have constructed references, teaching tools or speaker slide sets. To purchase these slide sets or to see its contents, try  
[www.secure.asco.org/prof/sh/f\\_sh.html](http://www.secure.asco.org/prof/sh/f_sh.html)
- THE GENETICS OF CANCER  
Pass this fabulous site on to your patients! Funded by National Cancer Institute, this site is also useful for health care professionals. Be sure to visit [www.cancergenetics.org](http://www.cancergenetics.org)
- THE ONLINE RESOURCE CENTER  
Congratulations to Betsy Gettig and Michael Banke for this fantastic resource! This webpage contains links to a number of categories ranging from professional and patient education, human genome news, laboratory information and support group resources.  
[www.pitt.edu/~edugene/resource](http://www.pitt.edu/~edugene/resource) ♦

## ListServings

### TELEMEDICINE; DIFFICULT CHOICES

Lyn Smith Hammond, MS

For those of you without access to the listserv, we would like to make you aware of some valuable resources recently compiled from members on two important topics.

Telemedicine, patient-professional teleconferencing with two way video cameras, was a recent subject on our listserv.

Some resources are:

- Dr. David B. Flannery, Medical College of Georgia, Augusta GA; ☎706-721-2809; [dflanner@mail.mcg.edu](mailto:dflanner@mail.mcg.edu)
- Sharon Smith Linard, Children's Hospital, Columbus OH; ☎614-722-3540; [slinard@chi.osu.edu](mailto:slinard@chi.osu.edu)
- Dr. Murray Feingold, National Birth Defects Center, Waltham MA; ☎617-466-9555
- Dr. Celia Kaye, University of Texas Health Sciences Center, San Antonio TX; ☎210-567-5195; [kaye@uthscsa.edu](mailto:kaye@uthscsa.edu)
- Joan Scott, OncorMed, Gaithersburg MD; ☎1-800-662-6763; [jscott@oncormed.com](mailto:jscott@oncormed.com)
- Becky Butler, ☎501-296-1736 or 1-800-358-7229; [Butlerbeckyb@exchange.uams.edu](mailto:Butlerbeckyb@exchange.uams.edu)

For parents with adverse pregnancy outcomes, these resources have been identified:

- Pen Parents connects families; ☎702-826-7332
- Pineapple Press publishes *A Heartbreaking Choice*, a newsletter; distributes *Life Line* by J. Reid, *A Mother's Dilemma* by W. Lyon and *A Time to Decide, A Time to Heal* by Minnick, Delp & Ciotti; ☎517-224-1881
- The Centering Corporation is a source for Pineapple and Wintergreen Press titles. Selections include: *Precious Lives Painful Choices* by S. Ilse; *Beyond Prenatal Choice; Difficult Decisions; An Abortion For Love* by S.E. Hodge; ☎402-553-1200
- *After the Sorrow* by S. Uhrich; ☎206-543-3753
- *Our Stories of Miscarriage: Healing with Words*, ed. R. Faldet and K. Fitton, Fairview Press, 1997,

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### SIG Update: DNA Diagnostic Labs

## MINDS, EYES, HANDS IN COMMERCIAL LABS

Alexis Poss, MS

Friends and colleagues with traditional genetic counseling positions may wonder how the rest of us spend our time if we're not seeing patients. A number of us choose to work in a diagnostic laboratory setting. We are viewed by our laboratories as the minds that blends knowledge of patient care and basic science with marketing and management.

Perhaps our primary role is to educate our clients and technicians.

Secondly, we are the knowledgeable pair of eyes that check everything over from linkage analysis cases and Rh incompatibility, to "saving" cells for further testing and billing clients appropriately.

Third, we are the hands who work the databases, coordinate research projects, launch new tests, review ethical dilemmas and supervise students.

We are the people at the diagnostic laboratories that you know will do the job you hope someone there is doing! ♦



## POLL RESULTS

### FUTURE CONFERENCES; WETLABS; MENTORING; FOUNDATION SUPPORT

#### FUTURE CONFERENCE SITE

*Cindy Soliday, MS, Chair, Annual Education Conference Subcommittee*

Of 1606 postcards mailed with PGC 20:2 about member preference to continue meeting with American Society of Human Genetics (ASHG), 366 (22.7%) members responded. The results were:

Choice	N	%
Hold stand-alone conferences	190	52
Continue to meet with ASHG	130	35
Undecided	46	13

The following represents those responding:

Full Membership Status	94
Associate Membership Status	2
Student Membership Status	4

Respondents began work:

	N	%
...in the 70's	32	9.0
...in the 80's	108	29.5
...in the 90's	182	49.7

Respondents reported the following attendance at NSGC and/or ASHG Annual Conferences:

	NSGC	ASHG
Always	39.6%	18.0%
Usually	48.1%	40.0%
Never	4.1%	23.8%

Comments supporting the respondents' choices included:

*In favor of meeting with ASHG...*

- Easier to get funding for NSGC and ASHG when back-to-back.
- Lower transportation costs when attending two meetings in same location.
- Can only go to one meeting, will be hard to choose.

*In favor of not meeting with ASHG...*

- Consider meeting with ACMG which is more clinically relevant.
- Hold NSGC in the Spring to accommodate those that do wish to attend ASHG.

The Board will discuss the long

range implications of this membership poll and our strategic position prior to a vote in October about further action.

#### WETLABS A "GO" FOR '99

*Kelly Ormond, MS*

As a result of a recent poll, the 1999 Annual Education Conference in Oakland will contain WetLabs. These are optional, intense, off-site learning experiences in com-puters, ultrasound and molecular genetics.

While the response rate to this poll was low, the committee looking into holding WetLabs felt there was enough interest to warrant giving them a try. Look for information in the Registration and Information brochure for the 18th Annual Education Conference.

#### FAX/E-MAIL POLL:

#### IS NSGC READY

#### TO CREATE A FOUNDATION?

*Lisa Amacker North, Finance Chair*

Six individuals responded to an article discussing the possibility of an NSGC Foundation, most encouraging us to consider a Foundation. Several offers of help came from people who had experience with grants and fundraising. One pointed out the headaches of finding members to oversee the process. We are still investigating the development of a Foundation and have scheduled a meeting at the Annual Education Conference in Denver to discuss future steps in nurturing an NSGC Foundation. ♦

#### MEMBERS MATCHED IN MENTOR PROGRAM

*Troy Becker, Mentor Match Coordinator*

The 1998 Mentor Match Program, sponsored by the Membership Committee, featured several changes as a result of suggestions made over the past two years.

- The questionnaire was redesigned to improve the quality and consistency of the matches.
- The yearly cycle was changed to an October 1 start date to make the program concurrent with student clinical rotation schedules.
- Mentors and students to meet at the Annual Education Conference, near the beginning of their relationship.

This year boasts the largest response since the inception of the program. Fifty counselors and 44 students have returned their respective questionnaires. Counselors agreeing to mentor come from all regions.

All students were matched within their top three specialty area requests. Ninety-six percent were matched within their geographic preferences: 50% with their first choice; 23% with their 2nd choice; and 23% with their 3rd choice. The remaining 4% were matched with their 1st choice for specialty area. ♦



# BULLETIN BOARD



## DIRECTORY SHIFTS

### PRODUCTION SCHEDULE

Good News! NSGC is growing!

More Good News! Our 1999 membership directory production has been rescheduled to represent the 1999 active membership, to help Special Interest Groups (SIGs) plan activities and to keep our numerous listservs current.

Here's the plan:

- Invoices for your 1999 dues will be mailed in early November. The final date for payment will be in mid-February.
- Your dues invoice will also request information about how you would like to be listed in your SIG directory for distribution to the public.
- The 1999 directories will be outsourced, saving precious staff time to concentrate efforts on our strategic plan and tend to your member needs.

(Temporary) Bad News! You will not be receiving your 1999 Membership Directory at the Annual Education Conference or in

the mail by year's end. Rather, the new directories will be mailed in the Spring. ♦

### ADMISSION TO EDUCATION SESSIONS AT ASHG IS FREE

Registered for NSGC but not ASHG? Staying an extra day? This offer is for you!

Registrants holding badges from NSGC's 17th Annual Education Conference in Denver will be able to attend ASHG's Education Session on Wednesday morning only. To take advantage be sure to keep your badge, as all rooms will be monitored. ♦

### NEW PUBLICATIONS IN 1999

- Julie Maley's dissertation, *An Ethics Casebook*, studies ethics in the genetic counseling setting using NSGC's Code of Ethics as a guide. Members may now purchase this book for \$12 +\$3 P&H for single copies; \$10.50/ea + \$8. P&H for multiple copies.
- "Cancer Risk Counseling: Working Hand in Hand with Physicians," by the Cancer Risk Counselors SIG Education Committee. Market your existing cancer risk genetic counseling services to professionals or start a private practice.
- "New Frontiers in Genetics: Genetic Counseling for Psychiatric Disorders," by the Psychiatric Disorders SIG.
- ...*Also, coming soon*
- "Counseling Ashkenazi Jewish Populations"
- "So You've Been Told: Your Baby Has..." series in Spanish.

Look for these other new publications in your Publication Order Form, which will be included in your October Membership Mailing. ...*And free to members*

- *Manual for Genetic Counselors in*

*a Research Setting*, written for the membership by the Social Issues Committee. To obtain a copy, fax or E-Mail your request to the Executive Office. ♦

### CONFERENCE TO HIGHLIGHT NSGC COMMITTEES

Be informed and involved!

Interested in knowing more about how NSGC functions? A display at the Annual Education Conference in Denver will inform members and prospective members about committee structure and activities. Committee chairpersons will be present at an informational booth. Come prepared to learn or ask questions about these exciting topics our committees are tackling:

- Student mentorship project
  - Minority recruitment
  - Job Search Manual update
  - NSGC listservs
  - NSGC homepage
  - Potential creation of an NSGC foundation
  - Increasing awareness of the Code of Ethics
  - Job description templates
  - *Perspectives* articles
- See you there! ♦

### AWARD RENAMED

NSGC is pleased to announce that the Best of the Submission Student Category, abstracts submitted by students for presentation at NSGC's Annual Education Conference, has been renamed **THE BETH FINE KAPLAN STUDENT RESEARCH AWARD**. The Abstract Committee will continue to judge the student submissions.

Persons wishing to donate to this fund may send contributions to the Executive Office. All contributions will be acknowledged to Beth's family and to the donor. ♦

*Perspectives in Genetic Counseling* is published quarterly by the National Society of Genetic Counselors, Inc. Send articles and correspondence to the Executive Office.

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• NSGC EXECUTIVE OFFICE: c/o Bea Leopold, Executive Director, 233 Canterbury Dr, Wallingford PA 19086-6617; ☎610-872-7608; Fax: 610-872-1192; NSGC@aol.com

The opinions expressed herein are those of the authors and do not necessarily reflect those of the editorial staff or NSGC.

*Next issue December 15*  
*Submission deadline November 10*

# EMPLOYMENT OPPORTUNITIES



■ **ORANGE CA:** Immediate opening for F/T or P/T BC/BE Genetic Counselor. Excellent organizational & computer skills req. Spanish desired. Poss fac appt commensurate w/ exp. Provide PN GC; tch & train GCs & med students; commun outreach; gather data; prepare reports for State Dept. of Health Svcs.

☛ Kathy Steinhaus, MS, UCI Medical Center, Dept Pediatrics/Genetics, 101 The City Dr South, Bldg 2, ZOT 4482, Orange CA 92868-3298; ☎714-456-6883; Fax 714-456-5330; kasteinh@uci.edu. EOE/AA

■ **PASADENA CA:** Immediate opening for BC/BE Genetic Counselor. Spanish speaking a plus. Join expanding PNDx ctr. Need motivated GC for busy PN team. Some local travel req.

☛ Melissa K. Crane, MS, Alfigen, 11 W Del Mar Blvd, Pasadena CA 91105; ☎626-666-3300 or 800-426-6467. EOE/AA

■ **SAN JOSE CA:** Immediate opening for BC/BE Genetic Counselor. Work with 3 other GCs, medical geneticist & 4 perinatologists in active PNDx setting. Involvement in some genrl genetics/cancer counseling. Oppty to partic in ongoing support group. Work w/ diverse pt population in San Jose & satellite clins.

☛ Lisa Andres, MS or Erin Kennedy, MS, Alfigen/Perinatal Associates, 2520 Samaritan Dr, San Jose CA 85124; ☎888-310-3999; Fax 408-358-8264. EOE/AA

■ **SOUTHERN CA:** Immediate opening for BC/BE. Genetic Counselor. Exp; bilingual (Eng/Span) pref. Provide primarily PN GC svcs to diverse pt population: AMA, XAFP (TMS), terat, DNA referrals. Become part of team supporting one of the largest providers of genetic services nationwide.

☛ Beth Bronstein, Genzyme Genetics, PO Box 9322, Framingham MA 01701-9322; ☎508-872-8400; Fax 508-872-5234. EOE/AA

■ **CHICAGO IL:** Immediate opening for BC/BE Genetic Counselor w/ masters from accredited GC training prog. Excellent interpersonal & organizational skills a must. Join growing Cancer Risk Clinic, Section Hematology/Oncology. All aspects of couns/case mgmt for family hx of cancer; coord molecular tstg; partic in rsrch protocols; oppty for tchg & rsrch; develop multidisc strategies for cancer risk assessment. Environment conducive to prof growth.

☛ Shelly Cummings, MS, University of Chicago Medical Center, 5841 S. Maryland Ave, MC 2115, Chicago IL 60637; ☎773-702-4749; Fax 773-834-0780. EOE/AA

■ **CHICAGO IL:** Immediate opening for BC/BE Genetic Counselor. Exp, Spanish pref, not req. All aspects of PNDx (U/S, terat, dysmorph), perinatal consults, some peds/newborns, occasional genrl/adult/cancer genetics; monthly outreach clin; prof educ.

☛ Jar-Fee Yung, PhD, Director, Genetics Program, Mercy Hospital and Medical Center, 2525 S. Michigan Ave, Chicago IL 60616-2477; ☎312-567-2283; Fax 312-567-7619; jfyung@mercy-chicago.org. EOE/AA

■ **CHICAGO IL:** Immediate opening for BC/BE. Genetic Counselor. Oppty to work w/ 2 other GCs in hosp/univ based genetics prog w/ full range of clin svcs. Work w/ clin geneticist/ pediatrician to estab Ctr for Jewish Genetic Disorders. Conduct comm ed about Jewish genetic diseases, coord commun-based Tay-Sachs carrier scrngs, work w/ hosp-based Gaucher prog. Develop a web site on Jewish disorders & maintain clin databases.

☛ Joel Charrow, MD, Children's Memorial Hospital-59, Section Clinical Genetics, 2300 Children's Plaza, Chicago IL 60614; ☎773-880-4462; Fax 773-929-9565. EOE/AA

■ **IOWA CITY: IA:** Immediate opening for Program Associate I. MS in human genetics, GC, nursing, public health or related field pref, or comparable BS plus directly related GC exp or equivalent. BC/BE desired. Nurses: IA License req. Coord & provide genetic eval & GC to pts & families seen in Reg'l Genetic Consult Svc; conduct educ progs re: genetics, genetic disorders, birth defects & GC.

☛ Janine McBride-Rahn, University of Iowa, Dept Pediatrics, Attn: #43, 200 Hawkins Dr 2633 JCP, Iowa City IA 52242-1083; Fax 319-356-4855. EOE/AA. Women & minorities strongly encouraged to apply.

■ **BOSTON MA:** Immediate opening for BC/BE Genetic Counselor. GC clin exp pref. Abil to work independently & interact closely w/ clin & rsrch teams. Multidisc prog closely coordinated w/ Dana Farber Cancer Institute: counsel pts w/ familial breast, colon & prostate cancers.

☛ Forward CV, a brief stmt of clin & rsrch interests & 3 references to: Kristen Mahoney Shannon, MS, Massachusetts General Hospital, 100 Blossom St, COX 640, Boston MA 02114; ☎617-724-1971; Fax 617-724-3166. EOE/AA

■ **FRAMINGHAM MA:** Immediate opening for BC/BE Genetic Counselor. 0-2 yrs exp & current working knowledge of molec tstg; ability to multi-task, good communications skills req. Daily interactions w/ a multitude of health professionals, answering inquiries re: molec tstg; assist in reviewing & reporting results.

☛ Beth Bronstein, Genzyme Genetics, PO Box 9322, Framingham MA 01701-9322; ☎508-872-8400; Fax 508-872-5234. EOE/AA

■ **HACKENSACK NJ:** Immediate opening for Genetic Counselor/ Manager Genetics Service. BC req, exp essential, managerial exp pref. Ability to interface w/ all depts: peds, OB/GYN, oncology. Half-time genrl genetic couns in busy PN/ ped service w/ developing cancer genetics svc. Half-time admin tasks: staff & intern s'vision, budgetary respon, commun outreach, grant devel, marketing & media relations. Admin cmte partic as requested.

☛ Sivia Twersky, MS, Hackensack University Medical Center, 30 Prospect Ave, Hackensack NJ 07601; ☎201-996-5264; Fax 201-996-0827. HMCGEN@aol.com. EOE/AA

■ **WESTCHESTER COUNTY NY:**

Immediate opening for BC/BE Genetic Counselor. Exp; bilingual (Eng/Span) pref. Provide PN svcs for various indications: maternal age, maternal serum scrng, terat exposure & U/S anomalies. Become part of team supporting one of the largest providers of genetic svcs.

☛ Beth Bronstein, Genzyme Genetics, PO Box 9322, Framingham MA 01701-9322; ☎508-872-8400; Fax 508-872-5234. EOE/AA

■ **BROOKLYN NY:** Immediate opening for BC/BE Genetic Counselor. Opening for GC to counsel: genrl genetics, peds, adult, sickle cell prog, some PN couns, newborn scrng, satellite clins, tchg.

☛ Ernest Lieber, MD, New York Methodist Hospital, Genetics, 506 6th St, Brooklyn NY 11215; ☎718-780-3264; Fax 718-780-3085. EOE/AA

■ **NEW YORK NY:** Immediate opening BC/BE Genetic Counselor. Exp & Spanish pref, not req. Join busy, diverse academic genetics clin w/ extensive PN & peds exposure. All aspects of PN couns: CVS, amnio, ethnicity scrng: U/S abnorm, MSAFP scrng, etc. Peds: specialty clins; Muscular Dystrophy, Craniofacial, & in-pt consults. Prof educ; oppty for clin rsrch.

☛ Barbara Isquith, MS, Columbia-Presbyterian Medical Center, MHB 9GN-9-421, 177 Fort Washington Ave, New York NY 10032; ☎212-305-6731; Fax 212-305-9058. EOE/AA

■ **STATEN ISLAND NY:** Immediate opening for BC/BE Genetic Counselor. Join comprehensive genetics prog: all aspects of PN/Peds, cyto, molec, & biochemical genetics labs. Specialty clins, support groups.

☛ Susan Sklower Brooks, MD, Comprehensive Genetic Disease Program, NYS Institute for Basic Research in Developmental Disabilities, 1050 Forest Hill Rd, Staten Island NY 10314; ☎718-494-5240; Fax 718-494-1072; ssbsi@webspon.net. EOE/AA

■ **DURHAM NC:** Immediate opening for BC/BE Genetic Counselor. MS from ABCG-certified prog req; min 1 yr exp pref. Enthusiastic, motivated, independent person w/ good communication & organization skills req. Join med genetics team involved in inpt ped consults & outpt evaluation in genrl ped genetics, metabolism & multidisc clins. Active program undergoing expansion w/ oppty for diverse GC clin activity, clin coord, rsrch & tchg.

☛ Send CV & 3 ltrs rec to: Marie McDonald, MD, Duke University Medical Center, Box 3528, Durham NC 27710; ☎919-684-2036; Fax 919-684-8944. EOE/AA

■ **GREENVILLE NC:** Immediate opening for BC/BE Genetic Counselor. Wide range of GC oppty: Peds, PN specialty, satellite

See next page



## EMPLOYMENT OPPORTUNITIES

... from previous page

clinics. Fac position w/ multiple fringe benefits.

☛ O.J. Hood, MD, East Carolina University School Medicine, Brody Medical Sciences Bldg, Rm 3E140, Greenville NC 27858-4354; ☎252-816-2525. EOE/AA, Accom ind w/ disabilities. Immigration Reform & Control Act Compliance

■ WINSTON-SALEM NC: Immediate opening for BC/BE. Genetic Counselor. Primarily peds duties in large, acad med institution. Exposure to broad range of ped & adult GC cases in genrl & specialty clins. Partic in prof & med school educ req. ☛ Must send CV & 3 ltrs of rec to: Daragh Marnane, MS, Wake Forest University School of Medicine, Dept Pediatrics, Section Genetics, Medical Center Blvd, Winston-Salem NC 27157; ☎336-716-2213; Fax 336-716-7575; Dmarnane@wfubmc.edu. EOE/AA

■ COLUMBUS OH: Immediate opening for enthusiastic, self motivated BC/BE Genetic Counselor. Some cancer genetics experience pref, not req. Join active, growing clin cancer genetics svc, rsrch & educ team. Oppty for growth & devel. ☛ Inquires: Charis Eng, MD ☎617-632-5632; Fax 617-632-4280; charis\_eng@dfci.harvard.edu or Judith Westman, MD ☎614-293-6694; Fax 614-293-2314; westman-1@medctr.osu.edu. Send CV: Judith Westman, MD, James Cancer Hospital, 300 West 10th Ave, Ste 519, Columbus OH 43210-1240. EOE/AA

■ DAYTON OH: Immediate opening for BC/BE Genetic Counselor. P/T w/ potential for F/T. Excellent org skills & ability to work independently essential. Provide GC on & off-site as part of a comprehensive genetics team. Opptys for PN, peds, adult onset & cancer couns.

☛ Evan Renneker, Human Resources Dept, The Children's Medical Center, One Children's Plaza, Dayton OH 45404-1815; ☎937-463-5417; Fax 937-226-8473; erenneker@cmc-dayton.org. EOE/AA

■ OKLAHOMA CITY OK: Immediate opening for BC Genetic Counselor. Exp req. Join new Genetics Section. Org, develop & deliver genetic svcs, outreach clins; create cancer genetic svc. ☛ Send CV, ltr of interest, & 3 ref: John J. Mulvihill, MD, Children's Hospital of Oklahoma, 940 NE 13th St, Div Genetics, Oklahoma City OK 73104; ☎405-271-8685; Fax 405-271-8696; john-mulvihill@ouhsc.edu. EOE/AA

■ PORTLAND OR: Immediate opening for BC/BE Genetic Counselor. Exp or training in cancer genetics or oncology pref. Creativity, flexibility desired. Join network of 4 tertiary care hospitals to play significant role in growth & development of innovative Cancer Genetics Prog. Join interdisc team involved w/ cancer prevention detection activities: cancer GC & tstg; prog development & marketing. Tch pt educ classes & assist w/ cancer risk assessment & commun cancer prevention/detection progs. ☛ Sheila Murty, Recruiter, Legacy Employment Svcs, Legacy Health System, 1120 NW 20th, Ste 111, Portland OR 97209; ☎503-415-5660; Fax 503-415-5200. EOE/AA

■ PORTLAND OR: Immediate opening for P/T Medical Geneticist w/ MD from accredited school of medicine w/ postgrad trng in medical genetics. ABMG-cert plus hold or eligible for Oregon medical license req. Add'l educ/trng in cancer genetics pref. Play signif role in growth & devel of innovative Cancer Genetic prog; provide leadership & devel in collab w/ Cancer Svc. Ability to facilitate innovative delivery of clin cancer genetics svcs: GC & tstg, pt educ w/in an

interdisc framework. Mail or fax CV.

☛ Sheila Murty, Recruiter, Legacy Employment Svcs, Legacy Health System, 1120 NW 20th, Ste 111, Portland OR 97209; ☎503-415-5660; Fax 503-415-5200. EOE/AA

■ PHILADELPHIA PA: Immediate opening for BC/BE Genetic Counselor. 3-5 yrs exp in similar setting; travel to satellite offices req. Provide GC to PN pts in a busy perinatal setting: maternal age, abnorm maternal serum scrng results, U/S abnorm & family hx. ☛ Beth Bronstein, Genzyme Genetics, PO Box 9322, Framingham MA 01701-9322 ☎508-872-8400; Fax 508-872-5234. Include salary expectations. EOE/AA

■ AUSTIN TX: See San Antonio TX

■ HOUSTON TX: Immediate opening for BC/BE Senior Genetic Counselor. Exp req. Seeking motivated, self-starting, individual to join multi-disc team, incl 4 GCs. in private genetics lab. Salary \$35-45,000 w/ benefits package. PN clin work, admin & supervisory duties, act as resource for referring MD's nationwide. ☛ Cathy Blanchard, Laboratories for Genetic Services, Inc., Human Resources, 7400 Fannin, #1200, Houston TX 77054; ☎713-798-9500 x132; Fax 713-798-9595. EOE/AA

■ SAN ANTONIO TX: 1) Immediate opening (San Antonio) & 2) Jan 99 opening (Austin) for 2 BC/BE Genetic Counselors. 1) Exp & Spanish are assets. Join full svc private practice genetics ctr: PN, some Peds & Adult. On site w/ PhD clin geneticists. Backup avail from Austin prog. 2) Join priv prac genetics ctr w/ emphasis on PN but growing Peds & Cancer progs. ☛ LaDonna Immken, MD, Applied Genetics 1524 IH-35 South, Ste 200, Austin TX 78704; ☎512-443-4363; Fax 512-443-5243. EOE/AA