Genetic Services: The HMO Model
Ronald Bachman, M.D.

DR. McCABE: Our next presenter is Dr. Ron Bachman, who is Chief of Genetics Department at Kaiser Permanente, Northern California. Dr. Bachman will describe the financing of genetic services in an HMO setting. Having said that, however, I think it's important to recognize that Kaiser is a different model from the typical HMO.

Please, Ron.

Also, while they're bringing that up, I again will comment that I think it's important to look at the amount of research that comes out of Kaiser in a variety of different areas, because it can be informative in everything from vaccine utilization to genetic services.

Dr. Bachman?

DR. BACHMAN: Thank you. I'm going to discuss the delivery of genetic health care in a large population, and I'm going to lean to both the clinical and financial aspects of it. The care must be organized, consistent, comprehensive, and cost-efficient, and I might add another C, that of being caring. One must consider the introduction of new technologies and the elimination of unneeded programs. Most programs suffer from an infrastructure that is too small.

The problem? Clinical genetics is the health care of a few, where genomic medicine, where we're heading, is the health care of all. Are we prepared? Probably not.

I should probably give credit to where I think I cribbed this from, which was an article by someone sitting at the table today, Dr. Collins. Thank you.

On one hand, we have the problem of clinical genetics keeping up with new genetic technologies. The genetic evaluation is labor intensive. The current barriers are financial, linguistic, cultural, and many more, and there are a limited number of genetic professionals. On the other hand, we have the problem of the primary care provider. The time needed for a genetic evaluation is quite long. There's limited training in clinical genetics for the primary care provider, such things as genetic testing, risk assessment, non-directive counseling, and psychological implications.

I would like to present our program, which we hope will overcome these problems. As Ed mentioned, I work for Kaiser Permanente in Northern California. In Northern California, we have more than 3 million health plan members, more than 4,000 physicians, and more than 34,000 deliveries each year.

As I mentioned in my introduction, we think our clinical genetic services are comprehensive, consistent, caring, and cost-efficient.

We are fortunate to be well staffed. We have five genetic centers that are strategically located throughout our Northern California region. We have 11 medical geneticists with subspecialty training, four Ph.D. laboratory directors for our molecular and cytogenetics laboratory, 53 genetic counselors, 17 genetic nurses, three metabolic nutritionists, and the support people for the professionals.

I'd like to give you an overview of our program. It includes prenatal services in clinical and

screening, neonatal services, ethnic screen, multispecialty clinics for common genetic disorders, the adult genetic services which include cancer genetics, clinical genetics, and screening; genetic laboratories and genetic education both for our providers and our members.

Probably the centerpiece of our program is our prenatal program. All prenatal patients get a genetic and ethnic questionnaire and a video presentation of our genetic services, which assists them in our informed consent and also the selection of the testing that they think is appropriate for them. There are genetic counselors available for discussing that with them. We also have an expanded alpha fetal protein program, with 80 percent acceptance, an advanced maternal age program. All prenatal patients get an anatomical screen, the so-called ultrasound level 1, which converts to a level 2 ultrasound if any abnormalities or questions are found.

We have prenatal cystic fibrosis screening, hemoglobinopathy screening, a fetal pathology program, and genetic counseling when indicated. Our ethnic screening program in the prenatal period includes hemoglobinopathy screening, thalassemia, Tay-Sachs and Canavan, and cystic fibrosis.

Our neonatal programs include clinical evaluation. This is for children born with birth defects or that are recognized as being unusual looking. We also have the standard neonatal screening, and we have a program called our Escape Baby Program. This is a computer tracking system for babies that get tested either too early or get out of the nursery before they're tested. We test for the standard four tests that I listed before, and we are in the process of planning a tandem mass spectrometry program.

Our screening and tracking programs really include a lot of cases. Last year we tracked over 45,000 cases. These are our prenatal testing, our neonatal testing, and our breast cancer and mammography tracking.

In clinical genetics, this is the clinical evaluation by the geneticist, or together with a genetic counselor, or by the genetic counselor alone. Last year we evaluated over 20,000 cases, and this includes case management when indicated, and there's quite a database for outcome studies.

The genetic counselors are sort of the glue that holds our program together. They provide genetic services on their own. In fact, they work autonomously in many different genetic type problems. They assist the clinical geneticist in case preparation. They are involved in case management, psychosocial support of the family, and genetic education. It's actually the genetic counselor which is my hope for the future in terms of the integration of the genetic counselor at the primary care level so there isn't a need for the primary care physician to learn all the genetics we are placing on him or her.

We also have a fetal pathology program, and we developed this because we were losing important genetic information for diagnosis of conditions and the recurrence risk for those families. Last year we had approximately 2,000 cases.

We also have a group of genetic multispecialty clinics staffed by experienced professionals providing care for these particular more common genetic disorders: spina bifida, craniofacial abnormalities, metabolic genetic abnormalities, pediatric lipid disorders, neurogenetics, a skeletal dysplasia clinic, and neurofibromatosis. When a patient is seen in these multispecialty clinics, the recommendations are given both in writing to the patient and their family, and to their provider. Also, our staff in these multispecialty clinics track the patients to make certain that they get appropriate care and that the recommendations that are made are carried out. This is done by

either our genetic nurses, our genetic counselors, or our metabolic nutritionists.

Multispecialty care is expensive but we think cost-efficient, because the patients are getting appropriate treatment, and that includes appropriate surgery. Last year we had over 2,000 patients in our multispecialty clinics. We also have a cancer genetics program where we do genetics risk counseling, and breast and colon make up the majority of it but we certainly do counseling for other genetic cancers. We provide gene testing when indicated, and as I alluded to before, we have a breast cancer tracking system and a mammography tracking system.

The mammography tracking system is for abnormal mammograms. This is not generally in the area that a genetics department works in, but because of our experience with tracking genetic conditions, we were asked to do the breast cancer and mammography tracking, and certainly we thought that the breast cancer tracking system might help us identify some families that had increased genetic risk for breast cancer. Last year in terms of our cancer tracking, we had over 3,000 newly diagnosed breast cancer cases, and over 23,000 abnormal mammograms that we tracked.

One needs dependable genetics laboratories, so we've developed our own in cytogenetics, where we've had over 11,000 cases last year; our molecular laboratory, over 24,000 cases; and we provide the molecular work for the Southern California Kaiser Permanente. Our metabolic studies go to Southern California Kaiser, where they have a metabolic laboratory. We find it very helpful to manage our own laboratories.

I probably, because of time, won't discuss this enough, but we think genetic education and research is very important. We have more experience with the genetic education than research. We provide an online publication for primary care providers which is less than 1,200 words. I'm a member of NCHPEG, and when we tried to introduce a CD-ROM that has six hours of terrific information on it, there were a limited number that had the time to review that. So we send out frequent emails, and they're available online, on issues such as hemoglobinopathy screen, who should be referred for cancer genetic counseling, guidelines for management of specific genetic disorders, and guidelines for who should be referred to genetics.

We have our own website that was developed, and although I must admit it was developed in terms of education of our members, our providers are using it a great deal so they are prepared for the questions of the members.

As I said, we don't have a lot of experience in research. We have the database, we've done a few studies, but not as many as we probably could.

Now I would like to talk a little bit about how we introduce new programs. First of all, it's the decision of the genetics group, and those are the geneticists and the genetic counselors. If we think a new technology should be introduced, we prepare a discussion with our new technologies committee, and if they approve it, we then submit it for the Kaiser Permanente budget process. We do this for large programs. We did it when we established a chorionic villus sampling program and when we introduced prenatal screen for cystic fibrosis. We are currently evaluating preimplantation genetic diagnoses and first-trimester screen for chromosomal problems using nuchal translucency.

After this process, we submit it to our administration, and if they approve it -- and it usually is approved if it's standard of care and cost-efficient, and we make a good case for it -- we establish a cost basis for the new service, we monitor our productivity and actual costs because the actual

costs usually aren't less but may be more than we projected, and each year our programs are reviewed and we have to submit a request for an annual budget. So they're reviewed both at the genetics level and also at the administrative level.

This year our budget is going to be over $24 million, although that includes a $3 million pass-through fee to the State of California for cooperation with them in the prenatal and neonatal genetic screening program. When I presented this information at the American College of Medical Genetics in 2002, I used our 2001 financial information and figured out that to provide genetic services for our health plan, it cost 52 cents per member per month. For 2004, that's going to go up to 65 cents per member per month, which is a significant increase, but that includes new programs, higher wages of staff, and more staff.

Last year we had 207 full-time-equivalent employees in our genetics department. We had 13 physician full-time equivalents. Now, you might remember that I mentioned we had 11 physicians who are geneticists, but we have to employ parts of physicians to help staff our multispecialty clinics, like our pediatric orthopedist or pediatric neurologist, and they charge their time to our genetics program. We saw over 103,000 cases last year.

Now, I figured out some cost information that might be of interest to you. Our clinical genetics was $384 per patient. The multispecialty clinics, as I alluded to, is quite expensive care, over $1,200 per patient. Our fetal pathology patients were $270 per case. Our cytogenetics was $362 per study, and our molecular studies were $121 per study. The cost seems high, but when you want to provide a quality program and try to provide everything that's standard of practice and include your overhead costs, it certainly is high. Genetics is expensive.

We made an assessment of what we're going to need in the future, and this was done in conjunction with a report from the Health Technologies Center, "Impact of Genetic Testing." We think that in the next two to five years the laboratory needs will be more gene testing, more prenatal genetic screening, more neonatal genetic screening, more carrier testing, more ethnic screening, and more predictive testing. In terms of personnel needs, we're going to need more geneticists, more genetic counselors, more genetic services done by the primary care providers, increased genetic education for primary care providers, increased genetic education for all our residents, and use of the Internet to make genetic services efficient.

Now, in terms of the next five to ten years, which I probably should have made five to fifteen years, where we're going seems to be in developing comprehensive genetic services, genetic practice guidelines, preimplantation genetic testing, chip testing for genetic disorders, SNP mapping, pharmacogenomics, and treatment in terms of stem cells, gene therapy, and proteomics.

Well, on my last slide I want to tell you what we think the solution is. First of all, a more efficient clinical genetics infrastructure. Even though we have a fairly good system, we are constantly honing it to make it better. As I mentioned before, we need more primary care genetic services, and I am of the belief that we can introduce genetic counselors within the primary care department to work alongside the primary care physicians, to evaluate perhaps genetic history and a pedigree that might have obtained by an Internet use prior to the patient coming into the program, and actually doing counseling for some of the more common disorders such as hemochromatosis, thrombophilia, and cancer at the primary genetic care level.

I think we're going to need to incorporate the Internet into genetic services for patient triage, collection of medical history information, pedigree construction and family history, and patient and provider education.

We are making some progress on this solution. I think we have established a cost-efficient program and hopefully a model for delivery of clinical genetic services to other large groups of patients.

Thank you very much.

DR. McCABE: Thank you very much, Dr. Bachman.

At this point we're going to take a 10-minute break. We will resume with the next presentation at 3 o'clock. Again, refreshments for members and ex officios are here in the room, and for others in the lobby of the hotel.

Thank you very much.

(Recess.)