

Burns, Joan

Personal Details

Name	Joan Burns
Dates	Born 1931
Place of Birth	USA
Main work places	Madison; Wisconsin
Principal field of work	Genetic Counselling
Short biography	Not available

Interview

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INTERVIEW WITH PROFESSOR JOAN BURNS, 24th OCTOBER, 2005

PSH. It's Monday 24 October 2005 and I'm in Madison, Wisconsin, talking with Joan Burns about the early development of genetic counseling programs in Madison and more widely in America. Can I go back Joan, and firstly ask you how did you come to get into this field in the first place?

JB. Well, in the first place, I came to the University of Wisconsin to attend graduate school in 1954. Jim Crow agreed to serve as my major Professor for a Masters degree.

PSH. That was in genetics?

JB. It was a Masters degree in Zoology and Genetics and my major professor was Jim Crow of the Genetics Department. For about 12 years after completing my Masters Degree I was at home raising children. Our third child has profound mental retardation and as a result I became interested in the field of mental retardation and began wondering how families found out about recurrence risks. I became involved in the Association for Retarded Children (as it was called at that time), and came in contact with social work professionals who were helping families deal with the many aspects of living with a child with disabilities. One of the women with whom I became acquainted was Norma Berkowitz, a clinical professor in the School of Social Work who trained practicum students at the Waisman Center. That contact and experience led me to pursue a second Masters Degree in Social Work. During my practicum training at the Waisman Center I became associated with John Opitz, who was responsible for genetics evaluations in the Developmental Disabilities Clinic. He continued his primary Clinical Genetics Clinics in the Genetics Department and I was able to participate in some of his evaluations there. In 1973, under John Opitz's guidance, I conducted some outreach research as an element of my degree in Social Work to assess what was going on in communities around the State, -what parents were learning about and in need of- regarding genetic services. The eventual outcome of this research was the initiation, during the next few years, of many outreach Genetics Clinics around the state.

After completing my MSSW, I was employed in the Social Work Section at the Waisman Center to train social work field students. Before very long I realized that what we really needed were Masters-level trained people in Genetics Counseling. John Opitz connected me back with the Genetics Department, although I had never really lost touch with Jim Crow. Interest from both the Genetics Department and the School of Social Work supported the notion of developing such a combined training program. To recruit my first class, I was given access to applications the Genetics Department had received to review those who indicated an interest, not only in research or the research focus, but also in genetics counseling and who might be interested in enrolling in a two-year Masters Degree program in these disciplines.

PSH. And how many did you have in your first class?

JB. Five.

PSH. And the year then was 1976?

JB. This was the first class. (Looking at a photo album)

PSH. 1978

JB. Right. I accepted them in 1976 and it was a two-year program so they became the class of 1978.

PSH. So you've got a nice book with all their details from the beginning.

JB. Well we do. Casey Reiser, who is my successor as Program Director, put this album together. I had collected many photographs of folks at different gatherings over the years but then we decided to sort them out and put together these yearly pages for the album.

PSH. That will be a very valuable document.

JB. Well, I love it. I'm not sure if anyone has paid much attention to it since I left but I do know that Casey posts composite photos of each class as they enroll.

PSH. Tell me, at the beginning, what kind of links and relationship was there between you and your training genetics counselors, and the folk involved in medical and human genetics. How did that work?

JB. Because I had the endorsement of the Genetics Department and much collaboration with John Opitz and his post docs in that first year we were able to arrange many interactions between the genetics counseling trainees and the post docs. We had joint case conferences and seminars and the counseling trainees participated in many of the clinical evaluations with the post docs. Also, the genetics department was very open to collaboration and I had a great deal of help from Jim Crow and the department chairs, Millard Sussman and Carter Dennison, during the ensuing years.

Initially I envisioned a joint degree between Genetics and Social Work, thinking that I would provide the counseling input from my social work position. We did the training at the Waisman Center in an interdisciplinary setting. The genetics department funded the position of a Medical Geneticist and 50% of my position. The other 50% was funded through the Waisman Center's federal grant as a Social Work Clinical trainer. I thought that there would be an interest for a crossover for social workers that wanted to get the genetics necessary for genetics counseling. It soon became apparent that applicants, who were primarily interested in obtaining a Masters Degree in Social Work, although the interest and willingness were there, didn't have the scientific background to really deal well with the genetics information. During the first couple of years, we did have some applicants who were primarily interested in social work, but then as we kept building up the applicant pool, more and more of the applicants were coming out of biological undergraduate degree programs so that it really did result in all of my students getting their Masters Degree in

Genetics. The School of Social Work was having difficulty justifying 50% funding for my position. There was interest in keeping the training program at the Waisman Center but my Social Work position was cut to 25% so that I could teach courses for the social work trainees in such topics as "Social Issues in Mental Retardation" as well as a human biology course for social workers. At that time Carter Denniston was chair of the Genetics Department and was successful in finding a way to fund me completely through Medical Genetics.

PSH. I'm just trying to think though, do you think the fact that you started off having a genetics degree was important in terms of being accepted by the medical genetics department?

JB. I think so. I think so. Absolutely.

PSH. Because when you are getting something off the ground it can be very difficult unless the, what you might call the parent department, accepts you as one of them.

JB. I definitely did feel comfortable in being accepted by the Medical Genetics Department. I think my clinical, research and teaching experiences while completing my Genetics degree with Jim Crow really was the strongest point for my being accepted by the department as well as the fact that I completed the clinical genetics portion of my second masters degree as well as that research done under the guidance of John Opitz. I often accompanied him on genetics rounds at Central Wisconsin Center for the Mentally Disabled.

In 1979, Ken Dumars, the Director of the Genetics Counseling training program at U.C. Irvine, spearheaded a couple of meetings of the Directors of the five functioning training programs at that time and ultimately a national conference to develop some guidelines for curriculum in training programs for genetics counselors. A major publication resulted from that collaboration.

PSH. Can I ask which were then the other centers that had got going by that time?

JB. The very earliest programs were initiated at Rutgers University and Sarah Lawrence College. The program at Rutgers had been discontinued by the time of the 1979 conference. The other programs functioning at that time were the two at University of California at Irvine and San Francisco, the University of Colorado and the newest program, ours, at the University of Wisconsin.

PSH. And were these all Masters courses?

JB. Yes. They've only very recently started thinking about adding a PhD track. Probably the ones who would be most likely to do so will be those directed by the NIH because they have a lot more resources to support research.

PSH. In these early years when you were getting things going, what proportion of the course was what you might call scientific and genetic, and

what proportion was more psychology and counseling? How did you manage to get that balance?

JB. It was probably 75% science and maybe about 25% counseling.

PSH. Do you think that shifted over the years, or is it much the same?

JB. I think it's pretty much the same. Over the years some of the educators involved in the training programs have written books on the counseling aspects primarily focusing on genetics and counseling. One of the first was Seymour Kessler and more recently we have incorporated a new publication by John Wilde in our counseling training.

PSH. Yes

JB. Initially we had to use courses available on campus such as a very large class in the department of counseling and guidance. I was able to have my students enroll in that class but it really had a very broad focus and not as helpful as we would have liked. There were also some classes in the School of Social Work such as one on the methods of social work. I was able to enroll my students in that class and the instructor attempted to design one of the discussion groups to meet the specific aspects of genetics counseling. After a few years it became evident that these more generic counseling and social work courses were not fulfilling our specific needs and we began designing our own counseling courses.

PSH. How about practical experiences? Did you manage to get placements and attachments for your students? Did that happen during the second year of their work? How did that work out?

JB. Well, they developed slowly. Initially, our clinical placements for students were primarily within the Waisman Center Clinics, which our medical genetics team staffed.

We were able to include students in the genetics evaluations in the Developmental Disabilities Clinic, the Genetics Clinic, the Bone Dysplasia Clinic and the Biochemical Genetics Clinic. I was responsible for the genetics counseling services in the Biochemical Genetics Clinic and utilized that for first-year training. It wasn't long before we had students doing placements at two of the hospitals. After Renata Laxova arrived she became engaged with more services at local hospitals. I recall going with her to talk with physicians about establishing genetic services in their clinics. Initially, these were primarily prenatal clinics and eventually she began providing services in the cancer clinics. Genetics counselors were involved with Dr. Laxova in staffing these clinics. In the beginning, Joanne Becker was the counselor in the Cancer Genetics Clinic and before long two other counselors joined the group and have been training students in that clinic. As we began to graduate some of our trainees many of those clinics were interested in increasing genetic services in the hospital clinics and hired our grads. This, of course, increased our clinical sites for our trainees.

A very important training aspect of the clinical experiences was the development of didactic sessions related to the cases seen in clinic. Each

clinic day was summarized with a case conference and, in addition, we held weekly clinical meetings to discuss the cases seen to explore the counseling issues as well as some of the science associated with specific conditions seen in clinic.

As the program evolved we began to develop new courses that expanded the basic knowledge that students received in their basic introductory work to include a stronger focus on the issues involved in genetics evaluations. Dr. Laxova developed and taught a clinical genetics course. Rich Pauli developed and has taught a course focused on literature search in genetics. One of our counselors who has been involved in teratogen counseling developed and taught a course in embryologic development. We also tapped some of the specialists in other disciplines to provide didactic experiences specific to our students' training, such as a course in cancer genetics taught by a physician in that area.

PSH. Who, in those early years, were your main metabolic genetic physicians or pediatricians?

JB. Harry Waisman pre-dates the initiation of the genetics counseling program. In the mid 1970s, Stan Burlow was here and after he left John Wolfe replaced him and has been here since.

PSH. When was it that you handed the program over? Was this just 2 or 3 years ago now?

JB. Well, I formally retired in 2000 but I was re-hired for a couple of years and during that time I switched more of my funding over to Casey Reiser, who was my Associate Director. A year or so later we began to search for a Program Director. Although we recruited broadly and widely and did interview a few applicants, Casey was hired as the new Program Director. She and I had worked together so beautifully for so many years so it was a seamless transition.

PSH. It was a smooth transition?

JB. Right. I was still here as she began in her new roll. That class in 2002 was the last class in which I was really involved. During the next couple of years I met with the class occasionally but my formal involvement ended in 2002.

PSH. What sort of size of class had you by then? Was it still pretty small?

JB. Yes, we've never gone over 5.

PSH. That's interesting.

JB. We felt as though the availability of clinical experiences for students dictated the number that we could optimately train. One can have any number of students in a lecture course or even in a lab course, but it's the clinical experience that is so very important to the training of counselors.

PSH. Is it difficult to maintain a course financially with just 5 people? Because I know from my colleagues it is very nice when you have a small number but you often need to have a larger number to break even.

JB. Absolutely, but one of the nice things is that I never had to really manage the budget within the limits of the tuition paid by my five students. The Genetics Department funded what we needed. They would fund our salaries and then I recruited all over campus to get people to help with additional class placements and clinic supervision. One of the financial problems we had some concern over was finding support for our students. Tuition has become very expensive. To some extent we have been able to employ them as teaching assistants in both zoology and in genetics. For many years, I taught a 100-level course in genetics and with that I was able to hire two teaching assistants.

At one point, with the help of Carter Denniston when he was Chair of the Medical Genetics Department, I tried to get the Dean of the Medical School to underwrite some of the costs of the program by providing a partial FTE for each of the clinical supervisors. I was never successful in doing that. All of the clinical supervisors are salaried for their clinical work. Many of them had been former students so they were always willing to take on the added work of supervising students in their respective clinics. When John Wolf became the Director of Clinical Genetics here at the Waisman Center and had contact with the Medical Genetics Department and the Dean of the Medical School, he was able to work out a budget beyond the salaries of the Program Director and Associate Director. That resulted, more recently, in some additional supplemental funding that Casey has been able to utilize, as she perceives necessary for the program.

PSH. I think it's the same everywhere.

JB. We have had to really strategize.

PSH. What kind of geographical area do you find your students come from?

JB. The United States of America. They have really come from far and wide. We do get quite a few from Wisconsin. We used to have the pick from the cream of the crop from mid-Western applicants but as more programs developed in the mid-West, we have some competition for the best students. While our students are primarily from the mid-West, we have had some from California, New York, and New England as well as one from Canada. Not all of our mid- Western students are state residents and we have often had classes with no Wisconsin residents. The lure for state residents is, of course, the lower tuition costs as compared with students from out-of-state. Wisconsin does have tuition reciprocity agreements with Minnesota so that is somewhat of a draw for applicants from there.

PSH. I noticed in that first photo you were showing me you've got one man in the class.

JB. In the first class there were two men. The one you see in the picture was an undergraduate here on the Madison campus. When he completed the

program he worked with Ken Dumars at the University of California at Irvine. After a couple of years as a genetics counselor he realized that it was becoming difficult for him emotionally. He returned to Wisconsin and pursued an MD degree in anesthesiology. The other man who was in that first class was Sean Phipps and he continued in the field of genetics counseling and pursued a PhD in psychology. The current students started an alumni website and Sean was one of the first to respond and stated that he remembers, with fondness, his involvement in the program.

We've had very few men in the program although we often had at least one man in the class. One year I admitted two men into the program but before long one of them realized this wasn't what he thought genetics counseling was going to be so he left. The other one, after a year in the program, transferred to a PhD program in the Genetics Department so that year our class was reduced to three students. There was a man in the class that just graduated in 2005.

PSH. How have you found the job prospects for the folk coming through and completing? Have there always been plenty of opportunities, or was there a phase at the beginning where it wasn't quite clear what they were going to do once they had finished their training?

JB. That's exactly the way it has been. However, we found, even in the beginning, that most found a position after about six months post graduation. Since there were only five programs graduating a small number of people there was a very small workforce going out each year seeking employment. Among the training programs that were operating from the beginning, some hired each other's graduates and we also found that we hired some to stay and help us expand the clinical opportunities for our program. As the professional community began to gain an appreciation for the roles that Genetics Counselors could play, more opportunities opened up. Some of the graduates have worked in other arenas besides counseling, such as with drug companies or in areas of research.

PSH. Tell me a little bit about the other centers because this is really the first American genetic counseling center I have visited and although I know vaguely about some of the others, I have not gone and talked to people. I mean that I have always understood that Sarah Lawrence College really was the one that started things off in the beginning. Is that right?

JB. It may well be, except I don't know if Rutgers started either a little bit before or after Sarah Lawrence but I believe that Sarah Lawrence was the very first. That program began to train in 1969.

PSH. I don't even know exactly where Sarah Lawrence College is.

JB. In New York.

PSH. It is? In New York State or New York City or somewhere between the two?

JB. I have a listing of the other programs. The address for Sarah Lawrence is Bronxville. That's close to New York City.

PSH. And am I right that it was Joan Marks who really was the moving spirit?

JB. Right. Yes, she definitely was.

PSH. I have not properly met her. I have seen her from time to time.

JB. I think she retired some time ago. I don't know whether she is still contactable. I don't think she goes to meetings anymore.

PSH. What was her background? Was she a social worker?

JB. Yes, she was.

PSH. So she didn't have a genetics degree.

JB. No.

PSH. Do you think actually that made an influence on how a person approached the subject? I can see it must have somehow.

JB. Well, she certainly was very knowledgeable and seemed to incorporate her perspectives as a social worker into an understanding of the impact of genetic disorders on families. I think this book about the early years of the program sheds some light on that.

PSH. I think it's got a historical chapter in it.

JB. Joan was very involved in pulling together the counselors who contributed chapters to the book, many of whom were graduates of the program at Sarah Lawrence. One of the contributors was Diane Baker who was a student at Sarah Lawrence and later became the Program Director at the University of Michigan.

PSH. We can come back to Michigan, but just thinking about Sarah Lawrence a little bit more, who was the person in medical genetics that Joan Marks linked with to develop things.

JB. I can't tell you that. I don't know.

PSH. I suppose it could have been someone like Kurt Hirschhorn, but it doesn't come immediately to your mind?

JB. No, and probably because back in those days I wasn't familiar with all of the people involved in each program.

PSH. Not to worry.

JB. I thought I had something in my files on the Sarah Lawrence program. That's why I'm looking through this file drawer. I recall having brochures on the various programs. Here is a paper by Joan Marks.

PSH. Thank you. That's certainly valuable, isn't it, because it's a report of the first eight years?

JB. Right. David Rimoin did a paper on manpower needs in human genetics, which I have here. Maybe I can make some copies of some of these for you.

PSH. This report lists the different centers you see which really corresponds very exactly with what you were telling me before about the main centers.

Just coming back to how things evolved, at what point did you start to develop strong links or collaborative meetings between the centers having genetic counseling courses?

JB. As I described earlier, we began to meet in 1979 when Ken Dumars initiated a series of meetings and conferences. These meetings were helpful for deciding what kinds of training ought to be in the programs. (Paging through some brochures and conference proceedings): Here is a list of how the various programs developed. That information is in the conversation we had earlier.

Here is the paper from the 1989 Asilomar meeting on Education in Genetics Counseling.

After that 1989 meeting, probably in the early 90s, we met following my suggestion that the program directors really ought to start meeting together and talking about curriculum development. This exercise did lead to the formation of the Association of Genetics Counseling Program Directors, which, officially started in 1993.

PSH. Were there any programs in Canada in this early stage that you linked with or was the pattern of service in Canada rather different?

JB. Well it is, as you know, very different. Roberta Palmer interacted with us early on and is still somewhat involved in Canada. They started a program at McGill relatively early. One of the issues that became a bit of concern when we started to certify Genetics Counselors was that their grads were not able to sit the exams for certification. I don't know if they had to change some of the policies for them to be able to sit the exam to become certified. McGill was the only one that I'm aware of that started early on. I think there is now another program but I'm not really up-to-date on this.

PSH. How about links outside the Americas? Are there now quite strong international links between the various centers?

JB. The best person to talk with about that is Betsy Gettig, the Program Director at the University of Pennsylvania.

PSH. How do you spell that?

JB. GETTIG. I expect that she and many of the others we have mentioned will be at the meetings you plan to attend. I don't know how much time you

are going to have to be in touch with them.

PSH. I can look out for them, that's the main thing.

JB. She has a good international link. Someone recently mentioned another counselor who was going to some meetings, I believe in England, but I'm not certain who that was. I haven't kept up with the international links. We have had, in the past, a couple of applicants from Europe but we have never had any students in our program outside the United States and Canada. I know that there are some stronger international links with some of our eastern schools.

PSH. I've asked you an awful lot of questions but are there things which you would like to put on record, as you might say, about what you feel the value and the contribution of, particularly your program, has been over the years?

JB. Well, I really think it comes down to the contribution that the profession of Genetics Associates (as we have called them after certification) has made. Our program contributed over a hundred Genetics Associates to the profession by 2002. I think that the overall contribution has been that this profession has expanded the opportunity for families to gain knowledge, information and support about the problems that are going on in their families when confronting a condition that may have a genetic component. Before the addition of Genetics Associates to the Clinical Genetics team, the Medical Geneticists didn't have the time and perhaps, in some cases, lacked the training to spend the extended time needed to deal with the needs families had to fully comprehend all of the information and deal with the emotional impact of the information. Genetics Associates, working with the medical geneticist, can help transition that information to the families and also follow along with families and aid in identifying further services that families may find helpful. With the advent of so many new diagnostic tests available in genetics, Genetic Associates, under the supervision of the Medical Geneticist, are becoming more helpful in being able to interpret some of the complexities to families without the actual presence of the physicians.

It is quite clear that the physicians dealing with genetic conditions have a wealth of knowledge that is critical to the evaluation and medical care of patients and so often cannot provide the more time consuming aspects of the larger concerns that families have. We have been fortunate to have Renata Laxova here to contribute her insights into the need for compassion and understanding of the broad aspects of dealing with patients to our training of the counselors. She has also infused these attributes in her teaching of medical students.

PSH. Do you think that the presence of the growing group of genetic counselors has also altered the practice and brought some of the more human and counseling aspects more strongly into the actual way the medical, clinical geneticists practice?

JB. I think so. Of course, as you know, my experience is very limited to what happens here in terms of what medical geneticists are doing, but certainly

those I deal with do bring those aspects into their dealing with patients. Of course, they do incorporate the participation of our Genetics Associates into their evaluations of patients.

Something that has concerned me lately seems to be a smaller cadre of post-docs electing the field of medical genetics. I wonder why that is. We have a wonderful new medical geneticist here at the present time but there doesn't seem to be a large number of available candidates from which to recruit to fill the positions of those who are retiring.

PSH. No, the numbers are never very large are they?

JB. The numbers do seem to be going down, or maybe it appears that way because the need has grown.

PSH. I'm sure that's part of it. Well look, I'm going to stop the recording now. But can I just say thanks very much indeed because I have learned a huge amount.