SEOPF: ACCOMPLISHMENTS

SEOPF has had many accomplishments in its 25 year history. Transplantation in the United States would not have the same shape, the same customs, or the same effectiveness had SEOPF not existed.

I will discuss a number of concrete contributions, but wish to begin with a tribute to a few of the less tangible, but, I suspect, equally important contributions. First, there were people at three institutions (Duke, Medical College of Virginia, and Hopkins), who thought that organ sharing would be necessary and that tissue typing would be an appropriate basis for organ sharing. These three centers shared kidneys with each other as a pilot program. With the success of these early experiences, a contract program was submitted to the Kidney Disease and Control (KDC) Program of the Public Health Service (PHS). There were eight institutions plus a private hospital who made up the original Southeastern Regional Organ Procurement Program (SEROPP). These were the Medical College of Virginia, Duke, Johns Hopkins, University of Maryland, Georgetown, University of North Carolina, Emory and Danville Memorial Hospital. SEROPP received contracts for the purpose of proving the feasibility of procuring organs in one place, preserving, transporting and transplanting them successfully. In addition, a method would have to be developed for funding the operation of the kidney sharing system. Later, additional funding was obtained from the Regional Medical Program. The aims and goals of the group rapidly grew to far exceed the limited concept of organ procurement. The SEROPP funding ended in 1973 with the

Medicare law which insured dialysis and transplantation. SEROPP then became SEOPF which incorporated in 1975 with 18 members. This group began to expand, and by 81 or 82 at the height of its influence there were 46(?) active members from New Jersey to Miami - and from Phoenix to Milwaukee. A rather large South and East. Transplant centers clamored for entrance. Why? They were experiencing difficulties in working out the pragmatics -- the mechanics of transportation, etc. They recognized the advantages of collaborative work, of frequent communication, and the strength inherent in multi-institutional collaboration. As a consequence, by the mid eighties SEOPF stood bestride the field. There was nothing else like it in the field of medicine. Nor has there been anything like it before or since. As a consequence, UNOS was molded, shaped, and largely directed by SEOPF, along with the American Society of Transplant Surgeons. Unfortunately, it has been downhill ever since. SEOPF is not what it was, and UNOS is certainly no SEOPF. UNOS came to be as a consequence of public demand, legislated by the people's representatives and implemented by their civil servants. It was and is comprised of a substantial number of unwilling participants compelled to cooperate by law, and that is indeed a great deal different from the participation of a group of passionate volunteers.

We met initially every three months and still meet every four months. Everyone complained that it was too often and too expensive. But, it wasn't. It was critical. These meetings were like great caldrons of activity boiling as vigorously as possible

without getting out of control and boiling over. There was great enthusiasm, everyone had a forum for their ideas. Data were shared. Ideas flowed freely and unselfishly. From this concensus did develop, judgements were made, action was taken, behavior was modified, and patients benefitted.

A familiarity developed among members of this multidisciplined group which led to mutual admiration, transfer of information and friendships that were close and enduring. These were some of the intangibles. Yet, my ability to describe them seems so inadequate - it was a state of mind. We knew we were ahead of the world; we were breaking new ground - solving problems - it was indeed a heady time.

What were the concrete contributions?

SLIDE 1

I) Multi-institutional Research:

The Scientific Registry

SEOPF members rapidly recognized the opportunity for multi-institutional research and alturistically set about to establish a scientific data base for mutual use. The Scientific Projects and Publications Committee was formed. It had some members appointed by the President, but anyone who expressed an interest would be appointed by the Committee Chairman. Membership was unrestricted and this Committee became a hotbed of interests, ideas and activity. Anyone could bring an idea to the Committee. If approved, a protocol was developed. After approval by the Board, if new data were required, the data acquisition committee developed

the appropriate instrument and the program was implemented.

Each center would collect these data, even though they did not necessarily regard it as important. Data coordinators developed and were paid by Medicare. As the data developed, there was some delay in analysis and publication. Ultimately it was agreed that anyone could access the data by protocol. Whoever did so, and brought forth a manuscript, could publish the data under their own name so long as SEOPF was given due credit. This proved a good stimulus. Subsequently 69 full length publications have come from this database. The timing of these publications is interesting.

Slide 2 (# of publications/year)

The peak activity was in 1984 and 49 of the publications took place between 1981 - 1987.

These publications are commonly quoted and the data are generally recognized as being among the best of its kind. Many important subjects were addressed. I have selected only a few to give a flavor of the effort. This selection is more random than purposeful based upon the ready availability of reprints.

Slide 3 (Bollinger)

The highly sensitized patient was the subject of several studies.

Slide 4 (Sanfilippo)

The effect of transfusions was approachable through our data base.

Slide 5 (McDonald)

An overview of the data base was published twice.

Slide 6 (Sanfilippo and Vaughn)

The detrimental effect of delayed graft function was first shown unequivocally by SEOPF.

Slide 7 (Sanfilippo, Vaughn, et al)

The relationship between HLA matching and renal allograft survival was analyzed several times.

Slide 8 (LeFor)

Regional crossmatch trays were a SEOPF innovation - developed to expedite transplantation of the sensitized patient.

Slide 9 (Vaughn)

Multiple organ procurement was shown not to be detrimental to allograft survival or function.

Slide 10 (Kramer)

The effect of Cyclosporin was placed into appropriate prospective regarding renal transplantation.

These 69 studies are a great legacy and would secure SEOPF's place in the history of transplantation if no other contributions had occurred.

Slide 11 (Contribution #II)

II) Computerized matching: SEOPF recognized very early that whatever standards were used, organs would have to be shared between groups in order to prevent wastage, and began to do that by computer. Substantial computer capability was acquired early and grew into the UNOS computer network.

Slide 12 (Stulting & Ward)

This paper was published to demonstrate the effectiveness of

the SEOPF computer program.

Slide 13 (Stulting & Ward #2)

Note that there is no bibliography to this paper since there were no previous publications on this subject.

Slide 14 (Contribution # III)

III) Sharing kidneys by HLA match: Perhaps due to the influence of Bernard Amos and his students, SEOPF early on embraced the idea that even though perfect histocompatibility is not practical for a large proportion of recipients of cadaver organs, partial compatibility can be attained by computerized matching and organ sharing, and would be beneficial. That is, a 6 antigen HLA match should be better than a 5 antigen match, etc. SEOPF tested this hypothesis and proved it to be correct, although the differences between 0 - 4 antigen matches are small. Intrinsic to this process was the idea, the concept, of organ sharing.

Slide 15 (Contribution # IV)

IV) Organizational Structure

We take for granted, today, the well-developed central organizations of SEOPF and UNOS systems which are so helpful for improving technology, coordinating harvest, and shipping organs. None of these were present. They had to be conceptualized, sold to the government, and implemented.

The concept of a global fee to be paid by HCFA for a transplantable organ was new. SEOPF proposed to place all charges into an organ acquisition fee so that HCFA could purchase an organ much like a heart valve. This was a very useful concept and

allowed SEOPF to secure funding for computer systems, data acquisition, training of personnel and clinical research.

The concept of a central clearing house for organ sharing originally called the Kidney Center was another SEOPF innovation.

Slide 16 (Williams)

This led to another study which demonstrated the effectiveness of the center.

It was ultimately simply transferred in toto to UNOS and today handles hundreds of calls per day from throughout the country concerning all transplantable organs.

Slide 17 (Contributions # V)

<u>The Development of UNOS</u>

The SEOPF group has functioned as if it had some metaphysical charter - some higher mission. It remains perhaps the most alturistic professional group with which I have ever been privileged to be associated. While SEOPF was thriving and growing in the early 80's, it seemed that we thought it was our mission to bring some order into this exploding field. For some time it was SEOPF policy to accept new members from contiguous territory only. This policy organization was thought to provide time for the foundation to assimilate new centers, and allow growth to occur in an orderly fashion. But, so many centers began to seek admission that the SEOPF Board, after open debate, elected to abandon that restriction and opened the door for more rapid national growth.

Some time during this period, centers from around the nation began to want their patients registered in a national pool. SEOPF

developed a computer program and implemented it for this purpose. This program was called the United Network for Organ Sharing. Organ sharing became a national activity. For the cost of computer time patients from the entire country could be registered for any organ that might become available to them. Thus, our resources and our expertise were made available to the entire country at no cost to them and no profit to SEOPF.

The fact is that SEOPF was the only organization in this country to address the issue of how the profession could deliver the service of transplantation to the population at large. Most of the scholars of transplantation were devoting their time attempting to make transplantation medically more successful and only a few were preparing to enable the care to be delivered on a national stage once it was more successful. SEOPF comprised that few.

Discussions took place officially and unofficially as to how this would be done. We favored a gradual but deliberate expansion of SEOPF. We talked about a Southwest and Northwest and Northeast Organ Procurement Foundation. This sense of urgency led to more rapid expansion. Unfortunately, time ran out. Immunosuppression suddenly improved, extra renal transplantation became therapeutic. The organ shortage became a public crisis and the public, media and political leaders were appalled to find that there was no national system --- no responsible body.

As these events were happening, we considered two possibilities; first, that SEOPF would simply become the national system by growth. The second possibility was that a national

system would be created de novo by the government. We hoped for the former, but we thought it prudent to prepare for the latter. Dr. Mel Williams was the presiding President of The American Society of Transplant Surgeons. He made his Presidential Address on the need for a national network, and he appointed a committee to try to establish it. Simultaneously, SEOPF appointed its own committee to establish UNOS as an independent national body. Those two committees, after working independently, decided to work together and they agreed upon appropriate Articles of Incorporation. UNOS was ultimately incorporated and was ready to compete for the federal contract as the National Organ Procurement and Transplant Network upon enactment of the Gore/Hatch National Transplant Act. In fact, UNOS was the only group which could have been given the contract honorably. So that is how it happened. The decision to break UNOS off from SEOPF was a fateful one. It resulted in the ascendency of UNOS and a decline in the influence of SEOPF. To this day, I do not know that it was correct or incorrect, right or wrong, or even good or bad. It was my intent, and I believe that of most SEOPF personnel that the National OPTN be as close a reproduction of SEOPF as possible. Not for selfish reasons, but because we believed it to be in the best interest of the country.

Obviously we did not succeed to our hearts desire, but we probably did as well as could be expected. In retrospect, we were quite naive politically. We thought the government wanted what was best for the patients. And they did, but only within certain

unspecified guidelines. We also thought that the remainder of the transplant community wanted the best national system possible. And they did, but many centers recognized that what was best for the country was not necessarily best for their own center, and that complicated matters considerably.

SEOPF has certainly had considerable influence in UNOS.

Slide 18 (Presidents of UNOS)

In fact, SEOPF people have served as President for 6 of the first 10 years of its existence.

There is much about UNOS that is not like SEOPF, but SEOPF certainly can be seen in the UNOS Board, its committee structure, its method of conducting business, and its day-to-day operation.

Slide 19 (Contributions # VI)

VI) Standards

All of these day-to-day, bread and butter issues of organ sharing were thought of, debated, agreed upon, and implemented by SEOPF. I do not propose that these matters would not have developed if not for SEOPF, but they were, in fact, standardized and implemented by SEOPF and have been largely adopted by the country.

Slide 20 (Contributions # VII)

VII <u>Transplant Coordinator</u>

The transplant coordinator is a new profession; one that is still forming. It is now specializing and finding its boundaries. It is my opinion that the transplant coordinator owes a large debt to SEOPF in assisting in its development. The

North American Transplant Coordinators' Organization (NATCO) is certainly their professional organization, but before there was NATCO there was SEOPF. Coordinators were committee members. They helped develop, set, and implement policy. They were encouraged in their development by SEOPF and its systems. The transplant coordinator is the only absolutely new professional to arise from transplantation and SEOPF played a major role in that development.

In closing, I wish to express my gratitude for being asked to give this address. SEOPF and the people who comprise it have been among my closest associates, and many of my happiest professional times have been with SEOPF. I would like to pay tribute to:

SEOPF's Past Presidents

Slide 21

and the recipients of her most distinguished service award - the Upjohn/SEOPF Award.

Slide 22

Finally, for those of you too young to remember, here are the three most critical figures in SEOPF history.

Slide 23 (Hume)

The great David Hume, one of the original Big - 3 in clinical transplantation in whose brain the idea began. He unfortunately died flying his own airplane in the mid 1970's.

Slide 24 (Amos)

Bernard Amos of Duke University, one of the pioneers of histocompatibility research who wanted HLA used as a basis for sharing organs.

Slide 25 (Pierce)

Gene Pierce was Dr. Hume's business manager at the time of the original idea. He continues at center stage as the Executive Director of UNOS. He has been called a national resource. Probably no one else knows the players in transplantation in the USA as he does.