

PROCEEDINGS OF THE NIKOLAS SYMPOSIA STEERING COMMITTEE

The Steering Committee for the Nikolas Symposia met on Friday, May 10 and on Monday, May 13. All members were present with the exception of Harris Pezoulas. Jeff Toughill was a guest at the second meeting.

Pre-symposium meeting, May 10:

This initial meeting was devoted to a discussion of the Trust being formed and preliminary consideration was given to a fourth symposium in 1992. The final program for this third symposium was made available by Tony. Jon indicated that his contact with the Lancet resulted in the journal's interest in publishing a conference summary-style manuscript that Blaise will be responsible for producing for the committee.

Post-symposium meeting, May 13:

#1) Brief additional discussion of the Trust was held. Paul will consider suggestions made by members of the committee and take necessary steps to establish the Trust as soon as possible. This will be the fund-raising vehicle for Paul and his family and friends.

#2) The following research thrusts were developed from the third symposium:

[1] The LCH lesion must be carefully and extensively phenotyped using immunocytochemical and molecular technology including double labelling. This is essential if one is to approach the matter of cytokine production and their effects.

[2] Clonality work using molecular techniques, RFLP in females, will provide valuable insight into the pathogenesis of LCH.

[3] Studies of LCH lesions for cytokine production and for the effects of cytokines, best done after the phenotyping work is completed, are necessary if pathogenesis is to be determined.

[4] More work is needed on the lineage and definition of the Langerhans cell including precursor cell identification and characterization in peripheral blood and in bone marrow.

[5] Langerhans cells and cytokines; what cytokines are produced by normal LC and pathological LC? What effects do cytokines have on normal LC and pathological LC?

[6] Detailed characterization of the pathology of CNS disease in LCH is still needed to illuminate the pathogenesis of diabetes insipidus and to characterize more completely the unusual occurrence of cerebellar dysfunction and other CNS dysfunction in subjects with long-standing LCH.

#3) It is intended that these six "research thrusts" be presented to the Histiocyte Society for review, prioritization and for publication to foster such research. This matter of process was discussed at length and it was agreed that the chairman should write Stephan Ladisch, President of the Histiocyte Society, to promote the following actions by the Society:

[1] Publication of the Society's newsletter listing the twelve research thrusts derived from the second symposium as soon as possible.

[2] Subsequent publication of the Society's newsletter by August 1 listing the twelve thrusts and the additional ones noted above. By that time financial support should have been defined and statements concerning this can be included along with directions stating how interested parties can apply for support.

[3] That the Society publish an add concerning research in the histiocytosis syndromes in prominent journals including the Am. J. Ped Hem/Onc, Lancet, Medical and Pediatric Oncology (MPO), Nature, New Eng. J. Med., Science. Peter Beverley will assist by drafting such an add.

The chairman will also indicate that the steering committee will invite the president of the Histiocyte Society to its post-symposium meeting annually. It will also be suggested that the Society issue a formal invitation to Dr. Hu to attend the Chicago meeting of the Histiocyte Society to encourage her to become active in the Society and to participate in research.

#4) It was proposed by the chairman that the committee approve the facilitation of Peter Isaacson's and Cheryl Willman's carrying out suitable studies concerning research thrusts 1 and 2 since data derived from such work is essential to further progress in determining pathogenesis of LCH, is needed as soon as possible and can begin quickly. This action represents a deviation from the established procedure concerning products of the symposia and is not intended to establish a precedent. The proposal was unanimously approved in motion form. The chairman will work with Peter and Cheryl to begin this work as soon as possible.

#5) It was agreed that the rapporteurs would have their reports transmitted by FAX to Tony by Wednesday, May 22 and that copies would be transmitted to the chairman the following day. Val's report had already been completed and given to Tony.

#6) Discussion, centered on the need for research material, resulted in the chairman's offering to develop short manuscripts on the use of surgical and autopsy material for this purpose, one in a form suited to lay reading and another in a form suited to medical personnel. The draft will be sent to members of the committee for review.

#7) It was agreed that the chairman would draft manuscripts concerning this and past Nikolas symposia, one for the Lancet and one for MPO starting as soon as he receives the rapporteur's notes from Tony.

#8) Attention turned to a discussion of a fourth symposium. Informal input from participants and information gained from the questionnaires supported the notion of a symposium in 1992.

It was agreed that the symposium could engender sessions on neuropathology and neuropharmacology and on pharmacology as it might relate to LCH. Individuals with knowledge of the action of VP-16 and Vinblastine at the molecular level and someone with expertise in anticytokine agents would be sought. Participants would be asked to present case studies of neurological manifestations and Siamon Gordon would be asked to consider the neuropathology of LCH assuming that material could be provided him. The chairman will look into obtaining material from Gordon Vawter's collection at Boston Children's and will be in touch with Siamon about this. Peter Beverley will consider next year's program and he invited additional suggestions.

#9) Jon Pritchard was asked to provide suggestions to the committee concerning his ideas for the fifth symposium.

List of tasks and assignments:

Peter Beverley

Program for 1992 symposium
Write ad concerning research

Tony Chu

Collect rapporteur's reports and develop formal report
Copies of rapporteur's reports to Blaise as soon as possible.

Jon Pritchard

Draft ideas for 1993 symposium by July 1, 1991
Contact Lancet concerning manuscript encompassing past symposia as well as current one

Blaise Favara

Continue contact with Peter Isaacson and Cheryl Willman
Develop drafts of manuscripts for Lancet and MPG
Develop manuscripts concerning research material
Write Stephan Ladisch
Investigate availability of LCH neuropathological material and work
with Siamon Gordon

Paul Kontoyannis

Proceed with establishment of Trust
Send Nikolas Symposia stationary to Peter Beverley and Blaise
Favara

Assignments are also highlighted on your copy of this communique.