I was less than 10 years old when Dr Carleton Gajdusek came into the Purosa Valley to carry out his research on kuru disease. Michael Alpers came after him and I worked alongside them to patrol out into the villages that were affected by kuru. My job was mainly to accompany Carleton and assist in collecting kuru patients’ samples and diagnosing their disease. I also worked as a kuru surveillance officer and went on my own into the villages to locate kuru patients. Sometimes, I was given the task by Carleton of transporting brain tissue and other selected internal organs to Kainantu station by tractor or Landrover.

The people’s belief system was that kuru was caused by sorcery as a means of payback by other clan members within the village or a nearby village. Collecting human samples was very hard owing to the fear of sorcery: the people feared that we might misplace some of the samples and sorcerers might pick them up. Nevertheless, those of us who worked with western medical scientists were free to move around in the villages to assist kuru patients and their families.

The others that I worked with in the field include John Mathews, John Colman and Jack Baker. It is great to meet again some of those colleagues I once worked with in the South Fore area of Okapa District.

Work among the people of the Okapa area from 1996 to the present

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I have conducted fieldwork on kuru, with colleagues from the MRC Prion Unit and the Papua New Guinea Institute of Medical Research (PNGIMR), since 1996. During this time, the fieldwork has been dependent on the support of the PNGIMR, and I thank the staff and the past and present Directors, Michael Alpers, John Reeder and Peter Siba, for their support. Michael’s vast knowledge and experience of Papua New Guinea has been invaluable and inspirational. I also thank my Papua New Guinean friends whose counsel has guided me through the occasional turbulent time. In particular, I thank Dr Inoni Betuela, Dr Ken Boone and his wife Lisa, Samson Akunaii, Anderson Puwa and Henry Pako. The members of the Kuru Project, past and present, have made a significant contribution to the success of the Project, and though I will not name them...
individually, it is important that their contributions be acknowledged in these proceedings.

The collaboration of the local communities in 22 linguistic groups has allowed us to collect over 4000 blood samples, other specimens and interviews. Their participation has been generous and, without it, our knowledge of prion diseases would be more limited. The Papua New Guineans who attended the meeting represented all those people from Papua New Guinea who have assisted in the research on kuru over many years.

Kuru is no longer a priority for the people affected: their health concerns are now focused on diseases that are no longer common in wealthy countries and on the emerging AIDS epidemic. For the duration of the project, we have tried to provide medical care where possible and to source external funding for development projects.

The team’s work is part of the ongoing research started by Vincent Zigas and Carleton Gajdusek in 1957 and there are many others, including some of those attending the meeting, who were the pioneers of kuru research. Much of the current research success has been dependent on the goodwill and integrity shown by the pioneers to the people of the kuru-affected region and to the long-term relationships established early on with those populations. We have tried as much as possible to follow the example set by the early research workers.

I also thank John Collinge, Frank Cooper and the staff at the MRC Prion Unit. There have also been other members of the MRC Prion Unit who have assisted in the fieldwork: Edward McKintosh, Skip Jackson, Toby Bentley, Edward Lagan and, most recently, Dafydd Thomas, who assisted with the clinical examination of patients.

I thank the Wellcome Trust for initially funding the project and, more recently, the Medical Research Council for funding support, the Life Neurological Trust for making a generous donation to the local preschools and the British High Commission in Port Moresby for funding the Okapa District Water Supply Project.

Finally, I would like to emphasize that the PNGIMR has contributed, and continues to contribute, to medical research at an international level, supports the annual Medical Symposium in PNG and publishes the PNG Medical Journal. It is important that the world sees Papua New Guinea in the positive light that it deserves.

In November 1966, I received, to my surprise, formalin-fixed pieces of brain tissue from a young kuru patient (Tabaso, female, 12 years) from Dr Michael Alpers at the NIH with the request for electron microscopy (EM). At that time, I was engaged in EM studies of infectious diseases of the central nervous system, especially of progressive multifocal leukoencephalopathy (PML), a conventional slow virus disease. I was delighted by the new challenge since my interest in kuru went back already to 1960. Through an epidemiology/neurology ‘network’ starting with Dr Leonard Kurland at the NIH, and extending to Prof. Francis M. Forster, in Madison, Wisconsin I had heard of this exciting new brain disease studied by Dr D. C. Gajdusek in Papua New Guinea. I received several reprints, which I also used for my teaching, but I was not able to obtain histologic slides for review since they had been sent to the Bunge Institute in Antwerp (letter by Marion Poms, NIH, to Prof. Forster, 18 January 1960).

In the autumn of 1966, I greatly enjoyed hearing follow-ups on the kuru ‘story’ while participating in the ‘Workshop on Slow Viruses’, sponsored by the Multiple Sclerosis Society, and held at the USPHS Rocky Mountain Laboratory, in Hamilton, Montana, 12–13 September. Dr Gajdusek reported on the disappearance of kuru as a disease of childhood, and that there had been an overall 40% decrease in cases, and Dr Clarence J. Gibbs discussed the transmission of kuru to chimpanzees. I had been asked to present additional data on PML. I also brought to the group’s attention the recent demonstration of paramyxovirus-