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Newsletter from the Association for European Paediatric Cardiology

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DESPITE MULTIPLE PROBLEMS, THE 38TH Annual General Meeting of the Association, held in Amsterdam, proved a great success. This is the more remarkable when it is appreciated that the entire meeting was organized within a period of nine months. This became necessary because of the uncertainty of the situation in the Middle East. At our Business meeting in Porto, therefore, it was decided to postpone the meeting planned initially for Istanbul. At very short notice, Jaap Ottenkamp agreed, with his team of willing helpers, to re-arrange the meeting in Amsterdam. We are all indebted to Jaap and his colleagues for their superhuman efforts. Initially, the plans and the programmes seemed to be going well, and many participants subscribed early. Unfortunately, after the breakout of the war in Iraq, and the recent outbreak of the epidemic caused by the virus responsible for the severe acute respiratory syndrome, the number of subscribers decreased. Indeed, registration almost stopped. Fortunately, in the last days immediately prior to the meeting, there was a "catch up" in those registering to participate. Our experience emphasizes yet again the difficulties and financial risks encountered in setting up meetings of this kind. At the end, nonetheless, we could be satisfied. There were enough participants. More importantly, we heard many positive remarks, especially about the scientific content of the meeting. The teaching course, devoted this year to fetal cardiology, was also well attended, and was judged to be of superior scientific quality.

The Congress was opened by Prof. Dr Herre Kingma, the Inspector-General of Healthcare, and Chief Medical Officer, of the Netherlands. He discussed the set-up and quality of centres dealing with paediatric cardiology and paediatric cardiac surgery, and the care provided for the patients attending these centers. These themes were echoed by Gary Webb, who delivered this year's Mannheimer lecture. The text of the speech of Professor Kingma is incorporated in this Newsletter. That of the Mannheimer lecture will follow in one of the forthcoming issues of the journal.

Text of the speech delivered by Professor Dr J. Herre Kingma.

Forty years of organised European Paediatric Cardiology: an inspector's view

"Life begins at forty"! The age of forty is a good moment to look back at what has been achieved, and to look forward and make plans for the future. Though today is its 38th annual meeting, the Association for European Paediatric Cardiology was founded in 1963. I want to congratulate you all on this fortieth birthday. Looking back, we see that the Association has grown from a small and very select group of paediatric cardiologists "gathered around the screen" into a large society for all physicians involved in the care for children with cardiac malformations or illnesses, with large audiences now attending the annual meetings. Over these forty years, the field of paediatric cardiology has also changed.

In the period prior to formation of the Association, knowledge increased about embryology, and the normal and abnormal development of the heart. Several extra-cardiac surgical procedures became available, and are now connected with the names of brave and famous men and women like Blalock, Taussig, Potts, and others. Hypothermia and cross-circulation opened the possibility for the first intra-cardiac procedures. Later, the development of the heart-lung machine promised new possibilities for intra-cardiac surgery, but only for children with a suitable weight. So, procedures to buy time became important. We learned to induce gains in weight in non-thriving babies, to prevent pulmonary hypertension, or to secure sufficient oxygenation. The development of the Rashkind procedure in the late seventies can now be considered the start of interventional cardiology.

With these changes in therapy, the patients also changed! Let me draw you a picture of some typical patients we saw in the Netherlands in the early eighties, when the Association came of age. The babies born in the first years of the Association had grown into adolescence. Each year, they met their fellow patients in a summer camp for youngsters with congenital cardiac malformations, the so called Hartenark, or "Heart Ark". The first day in camp was always emotional, because some of the friends from last year could no longer come. They had died, or they were too severely handicapped to be able to attend. Others, who did come, could no longer join all the games, and now needed a wheelchair to move around outside the building. These were children with a ventricular septal defect born before open-heart surgery in babies was possible, who suffered from Eisenmenger's syndrome. In these years, newborn babies with a ventricular septal defect were carefully nurtured until they gained sufficient weight to undergo open-heart surgery and total surgical correction. Children with more complex malformations were offered palliative surgery, sometimes with functional if not anatomical correction. The babies with deficient ventricular septation now had a good chance to grow up to healthy adults. The children undergoing palliative operations probably have met with more medical problems. They are today's adolescents and young adults with chronic cardiac problems.

Paediatric cardiology today

The increased survival has resulted in an ever-growing population of adults with congenital cardiac disease. Looking at the program, the Association is well aware of the problems for these grown-ups with congenital cardiac defects, and there is ample space for such problems in this year's programme. Not only an abstract meeting and a working group session, but also the Mannheimer lecture, to be given by Dr Gary Webb, and the "State of the Art" lecture by Dr Michael Gatzoulis, will address this topic.

Outside paediatric cardiology, however, both patients and adult cardiologists appear to have little knowledge of what they can expect. A recent survey among Canadian patients aged from 16 to 72, and referred to a centre dealing with adults having congenital cardiac disease, revealed a poor level of knowledge amongst the patients. Almost two-fifths were unaware of their own cardiac condition, including patients who had undergone repair of tetralogy of Fallot, the Mustard procedure, those with severe aortic or pulmonary stenosis, those with Eisenmenger's syndrome, and patients with tetralogy or ventricular septal defect who had not undergone surgery. Although more than four-fifths knew they should use antibiotic prophylaxis against endocarditis, almost half of them did not understand why they needed it.[1] Adult cardiologists seem equally unaware of the special needs of adults with congenital cardiac malformations. In the Netherlands, the second evidence-based guideline for heart failure was published last year. The multidisciplinary working group contained every conceivable discipline except paediatricians and paediatric cardiologists. The 200-page document contains practically everything known about etiology, diagnostics, therapy and lifestyle, but not even once does it mention congenital cardiac malformations, possibly *the* most rapidly growing cause for heart failure in adults.

In the last decade, improvements in diagnostic procedures, progress in cardiological interventions, and close co-operation between interventional cardiologists and cardiac surgeons, have made it possible to replace many palliative or partially corrective procedures by corrective operations. This often involved hard decisions. For instance, the Mustard operation, which was shown to offer survival and functional correction, was replaced by the arterial switch, which promised full anatomical correction, but was initially accompanied by high peri-operative mortality. Medical and technical improvements now allow intra-cardiac surgery even in premature babies. The rapid changes in technique, however, make it difficult to acquire and maintain the routine skills of the cardiologist and the surgeon. Innovation is not only paid in euros, but also in the lives of some of these young chidren. It is a challenge for our Inspectorate to discriminate properly between these investments in progress, and the sometimes unavoidable injury, as opposed to medical hubris and avoidable error and injury.

Today, interventional techniques account for the majority of paediatric cardiac catheterisations. These require greater skill than mere diagnostic procedures.

Moreover, some of the procedures, because of their complexity, may necessitate joint approaches between the interventionist and the surgeon, or surgical standby cover, along with the availability on-site of a paediatric cardiac intensivist and paediatric anaesthesiologist. This makes high demands on the training and expertise of all persons involved in paediatric cardiology, including doctors, nurses, and technicians. A question of paramount importance, therefore, is whether we are able to provide all these services in each centre at a sufficient level of quality and safety 24 h around the clock.

Today's paediatric cardiology is largely governed by guidelines, such as those provided by the Association for European Paediatric Cardiology. One such guideline prescribes that all equipment used in catheterisation should be specific for children of all age ranges. Attempts to use equipment designed for

adults, but modifying it for use in children, are strongly discouraged. The wisdom of this advice is underlined by a recent fatal result of such an attempt in this country. This guideline also advises sensibly that only a person trained in the investigation of congenital cardiac disease should perform cardiac catheterisations in adults with congenital cardiac malformations.

Future challenges and prospects

What are the future needs and demands? The results of treatment have been improving steadily over the past forty years. Nevertheless, there are still a lot of problems to solve. On the one hand, there is the increased population of adults with chronic conditions due to their congenital cardiac malformation, and the relative unfamiliarity of adult cardiologists with these problems. On the other hand, the ever-changing interventions in small children require specific skills, both for their performance, and to teach them to others. The wide range of possible malformations also indicates that specific skills may only rarely be used by a number of cardiologists. Registration of the outcomes and complications, therefore, together with regular reviews of performance by audit, and comparison with internationally available data, is necessary if we are to ensure optimal quality and safety of care. Last, but not least, ongoing research, especially in the molecular basis of congenital cardiac malformations, is needed to mitigate or better prevent the chronic conditions that still result after cardiac surgery.

Will all these demands ever be met in units with only a small staff? Ten years ago, in 1993, a committee of the Dutch National Health Council advised the Minister of Health to reduce the number of centres providing tertiary services in paediatric cardiology in this country so as to preserve sufficient skills, and to facilitate research and teaching. For whatever reason, these attempts to achieve concentration of services did not succeed.

I would like to make an urgent call to the professionals themselves to join forces and invest in team-building. You must look beyond the boundaries of your own hospital, and even your own profession and your ego. With the help of the new information and computing technologies, we might even be able to create a totally new virtual centre for congenital cardiac malformations. Such an approach, with locations in different hospitals, would create a network, where expertise can be exchanged on line, knowledge of rare conditions can be assembled, and patients with rare conditions can be directed to the hospital with the best expertise in that specific disease. Telemedicine can be used for interpretation of diagnostic procedures from other sites, for education, and for the performance of complex procedures, with feedback from an expert at another centre. Such online exchange of knowledge may offer competition for the exchange of knowledge during congresses such as this annual meeting organised by the Association for European Paediatric Cardiology. My proposal for the creation of a virtual hospital may seem Utopian, but I consider it an important avenue of progress, and a way to maintain quality and safety for our patients. At the age of forty, we have two choices. Either we sit back, and are proud of everything that has been achieved, or we look forward, and try to reach the top in the interest of our patients.

The choice is yours.

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