



## Twenty-four Years Later and Things are Changing...Some Good, Some Not

Several years ago, an editorial I wrote, "Twenty Years Later and Nothing Has Changed," appeared widely in a variety of dental publications. The content addressed my observations of dental care as it applied to individuals affected by the ectodermal dysplasia syndromes during the first 20 years at the National Foundation for Ectodermal Dysplasias (NFED). That article was the impetus for some changes about which I am both happy and disappointed to report. But let us begin with the good news.

When the first article appeared, Dr. Mike Kanellis at the University of Iowa College of Dentistry offered to host a meeting that took place in the spring of 2001. Key individuals representing not only the various dental specialties but also a geographic cross-section of the United States were invited. It was there that work began on what became *The Parameters of Oral Health Care for Individuals Affected by Ectodermal Dysplasia Syndromes*, which the NFED published in 2003. This publication provides families and practitioners with a clearer understanding of treatment expectations during a patient's life span. This document is also an important reference for insurers interested in treatment guidelines.

Interest in that document ultimately led to a workshop in the fall of 2004 that was jointly sponsored by the Center for Advanced Dental Education at Saint Louis University, Southern Illinois University School of Dental Medicine, and the NFED. Key individuals from 17 dental schools, 4 implant companies, 5 professional dental organizations, the National Institute for Dental and Craniofacial Research, and the Department of Maternal and Child Health attended. The workshop, *Access to Oral Health Care for Individuals Affected by Ectodermal Dysplasia Syndromes*, featured an outstanding faculty that addressed the complex treatment problems that these patients encounter. The response to the event was better than we could have anticipated, and we will soon have a network of dental schools providing coordinated care. Our goal was to enable every patient affected by an ectodermal dysplasia syndrome to receive care within an 8-hour drive. I expect that the goal will soon be met.

Another important result of that meeting was a shared belief that a better job could be done collecting research-oriented patient data. To that end, a group of dentists will join with us in November 2005 to create a data collection tool that will enable us to obtain useful information, such as tooth eruption patterns or information on the outcomes of various treatments. My hope is that this effort can be coordinated with clinicians around the world from whom we are also collecting information.

We have a new booklet for children titled *Carver's New Smile*. It is filled with full-color photographs that show vir-

tually every aspect of the dental experiences encountered by children affected by these unique conditions. Our goal for the publication was to prepare children for what to expect when they visit the dentist to receive their dentures. The book reduces fear, enhances cooperation, and optimizes expectations for success.

Lastly, thanks to generous donors, we have been able to make up to \$200,000 available through our Treatment Fund in each of the last several years to assist individuals who are unable to afford the extensive dental treatment they need. Our goals – making certain no child enters school without dentures or that the absence of a smile prevents employment for an adult – are coming closer to fruition. We are very proud of all of these wonderful accomplishments.

My biggest disappointment, which is shared by the dentists who review applications to our Treatment Fund, concerns patients and the treatment plans they receive. Our Treatment Fund receives many applications for financial assistance with care plans ranging between \$60,000 and \$80,000. While one may agree that these plans will provide an extraordinary level of care, few patients or their families are in a position to pay for them even with financial assistance from the NFED. Basically, our families are given only 1 option, which is to place dental implants in both the mandible and maxilla and to do ridge augmentation on both arches. These costs, not to mention those of the needed prostheses, continue to escalate. Rarely are families given alternatives that may work nearly as well and will be substantially less costly. Families who typically are unfamiliar with possibilities and alternatives are compliant while mortgaging homes, pledging retirement funds or taking multiple jobs just to provide the best care for their children. One clinician told me, "My job is to give my patients the best care. I don't look at the size of their wallet." When care costing this much is suggested, the clinician has a moral and ethical obligation to present alternatives that enable patients and their families to make appropriate decisions.

Unquestionably, we have seen improvements in the last 4 years and for that I am appreciative. However, there is still room for more. My hope is that dentistry will be an important partner in that effort, and that next year's 25<sup>th</sup> anniversary of the National Foundation for Ectodermal Dysplasias will provide even more reasons to celebrate.

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National Foundation for Ectodermal Dysplasias

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