ELSO RECOMMENDATIONS FOR
FOLLOW-UP FOR ECMO PATIENTS

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PURPOSE: The ELSO Recommendations for Follow-up for ECMO Patients is a document developed by the Extracorporeal Life Support Organization (ELSO) as a reference for physicians and health caregivers responsible for the follow-up of any patient who has been treated with extracorporeal life support. It is recognized that patients will differ in their needs, and centers will differ in their approach to the follow-up procedures for these patients, but it hoped that this document could provide useful reference material and support for the follow-up needs of the ECMO patient.

I. OVERVIEW

A. Discharge Planning

The transition of the infant's care from the NICU to the community physician is crucial. Responsibility for medical care must be clear. Additionally, ECMO infants often need more extensive care than is routinely provided in a primary care facility. Extensive communication between providers in the follow-up clinic, primary care facility, and parents is important to insure that routine pediatric care and special medical services are adequately provided. Communication with the infant's pediatrician should start with the discharging physician prior to discharge. Preparation for discharge of the ECMO should include:

Neurodevelopmental Assessment
Audiology Evaluation
Eye Exam per individual institution guidelines
CT/MRI

Appointments with primary care physician and necessary medical specialists should be made prior to discharge.

The discharge summary and information about ECMO should be sent to the primary care physician immediately.

B. Community Education

Parents frequently express concern that the professionals in their communities are not familiar with ECMO. It is important to provide information and educational materials to the hospital to which the infant is being transferred back, as well as to the primary care physician. It is suggested that a brief handout explaining the ECMO procedure and current knowledge medical and developmental follow-up be sent with the baby and mailed to primary care physician. Guidelines about follow-up should be included. It particularly important that the family and physician understand that routine pediatric care will not be provided by the follow-up program; **the child should be seen by the primary care physician for well baby visits and routine pediatric care.**

C. Importance of Parent Education

Parents consistently report that taking their baby home is frightening. They need ample time to discuss the baby's discharge status, follow-up needs, and any general concerns that they might have. They are usually reassured by having telephone numbers of ECMO team members that they may call if concerns arise in the post-discharge period. It is important that crucial information is given to parents in writing, preferably in the form of a manual. Parents do not remember all that is said to them at the time of discharge, and having written material to refer to is reassuring.

Many parents feel that the weeks following discharge are particularly stressful and lonely. Some parents would like to participate in a parent support group. They should be given information about groups in their area for reference.

Some ECMO programs teach their parents CPR before discharge. Others feel that this unnecessarily raises parents' anxiety. Consider teaching CPR to parents of all NICU patients so that the ECMO parents do not feel singled out.

D. Specialized Follow-up

Medical examinations should be repeated. If the child is receiving good pediatric care, further medical evaluation may not be necessary. Programs with the resources are encouraged to have a medical evaluation at each visit to supplement regular pediatric care. Closer follow-up is needed if there is an abnormal predischarge evaluation and/or abnormal head ultrasound or CT scan.

Follow-up evaluations are an opportunity for parent education about developmental milestones, referral for intervention, and for observing signs difficult parent-child interaction. Discuss parents' concerns about behavior problems and behavior management.

If the family lives nearby, schedule follow-up at your center. If they live at a distance, you can arrange follow-up at the closest High Risk Follow-up Clinic. A directory of ECMO Follow-up Programs is being compiled and will be available soon.

Examples of appropriate developmental tests are included with the guidelines, which follow. These are meant as suggestions only, and individual may wish to substitute or supplement them with others according to the training and expertise of the examiners. Prior to one year of age, a screening instrument such as the Denver II combined with a neurological exam is sufficient to pick up significant developmental abnormalities. A more formal and thorough developmental evaluation using the Bayley Scales of Infant Development or Gesell are suggested at one year of age to pick up more subtle deficits. From ages three to five, cognitive functioning is more appropriately assessed with standardized intelligence tests such as the McCarthy Scales of Children's Abilities, the Stanford-Binet, or the Wechsler Preschool and Primary Scales of Children's Abilities-Revised. Results of tests are usually accepted by public school systems to qualify children for special educational services.

Further language evaluation is suggested beginning at age two, as deficits in language processing are frequently documented. The Peabody Picture Vocabulary Test - Revised is a test of receptive vocabulary, but may be to administer to younger and more impulsive children. Language surveys may be given to the parent/caretaker for an estimate of expressive language. More sophisticated measures of language processing and expression are available for children ages three and above.

Finally, social immaturity and behavior difficulties are frequent concerns in risk populations. Informal assessment of social/adaptive functioning is appropriate through age three. Standardized instruments such as the Vineland Adaptive Behavior Scales and standard behavior checklists are useful obtaining community referrals and intervention services for preschool and school-aged children.

Referrals to medical subspecialties and intervention services should be provided as appropriate.

A written summary of the evaluation should be provided to the parent and primary care physician.

E. School Entry

Although most patients will have average intelligence when they enter kindergarten, they remain at increased risk for specific and subtle cognitive deficits that may affect school performance, but that may be missed by routine kindergarten screening. Therefore, a complete cognitive evaluation by a clinical psychologist or neuropsychologist is recommended prior to first grade. Parents should also be made aware that public law

mandates that public schools provide a free and appropriate educational program for each including intervention services for deficits that interfere with academic functioning (such as speech and language therapy, occupation therapy. Parents can obtain information about their rights in regard to special education services from their state Board of Education.

F. Pediatric ECMO

Pediatric ECMO warrants the same careful follow-up as does neonatal ECMO. Parents and physicians should be in agreement regarding the provision of medical subspecialty follow-up and routine pediatric care. Parents' medical, behavioral, and developmental concerns should be addressed fully.

II. AT DISCHARGE

A. Medical exam
- ♦ monitor growth and feeding
- ♦ residual lung disease
- ♦ incision site

B. Neurodevelopmental exam
- ♦ evaluate posture, tone, movement, primitive reflexes, sensory function, adaptive behavior

C. If normal, contact family by phone for update and to address any concerns. n schedule first follow-up within 6 months.

D. ***IF ABNORMAL: FOLLOW-UP WITHIN 2 MONTHS***

E. At discharge and at all evaluation periods:
- ♦ Anthropometrics
- ♦ Parent education
- ♦ Communication with pediatrician

III. 4-6 MONTHS

A. Medical history, physical, and neurological exam (as above) - repeat BAER if abnormal

B. Neurodevelopmental Screening (Denver II, Bayley, or Gesell)

C. OT/PT evaluation and treatment if motor delay

IV. ONE YEAR EVALUATION

A. Medical history, physical, and neurological exam (as above) - Behavioral hearing evaluation

B. Neurodevelopmental exam

C. Formal assessment with Bayley or Gesell

D. OT/PT evaluation and treatment if motor delay

V. TWO YEAR EVALUATION

A. Medical history and physical (as above)

B. Neurodevelopmental exam (as above, Bayley, Gesell, or Binet)

C. Behavioral audiometry if not done at 1 year

D. Language screening (e.g., PPVT-R, Language Development Survey)

E. Nutrition counselling and low cholesterol diet for family

VI. THREE YEAR EVALUATION

A. Medical history and physical exam

B. Neurological exam

C. Neurodevelopmental exam: formal assessment with Stanford-Binet, Gesell or McCarthy

D. Language screening (e.g., PPVT-R, verbal scales from the Stanford-Binet or McCarthy)

E. Social/Adaptive functioning (e.g., Vineland Adaptive Behavior Scales, Child Behavior Checklist)

VII. FIVE YEAR EVALUATION

A. Medical history and physical/neurological exam

B. Neuropsychological evaluation:

♦ General intellectual functioning: WPPSI-R, McCarthy, or Stanford-Binet

♦ Language screening: PPVT-R, verbal memory (e.g., verbal tests from the McCarthy or the Wide Range Assessment of Memory and Learning)

♦ Visual-motor integration (e.g., Developmental Test of Visual-Motor integration)

♦ Behavior screening (e.g., Child Behavior Checklists or Conners' Behavior)

♦ Questionnaires, parent and teacher reports

VIII. PEDIATRIC (RESPIRATORY/CARDIAC) ECMO:

A. UNDER 4 YEARS OF AGE

♦ Medical subspecialty follow-up (specific to disease process)

♦ At Discharge, medical exam including neurological assessment, and CT scan

♦ Additional follow-up as per Neonatal Follow-up

B. AGE 4 AND UP

♦ Medical Subspecialty follow-up

♦ At Discharge, medical exam, full neurological assessment (pediatric neurologist preferred) and CT scan if indicated from previous studies.

♦ Within 6 months after discharge

medical and neuropsychological evaluation

♦ > 6 MONTHS AFTER DISCHARGE

medical and neuropsychological evaluations as indicated

IX. References for selected evaluation instruments:

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Approved 10-94
Reviewed, 01-97, approved with no changes