

AB113. Experiences from coordinating parents whose child with positive results of newborn screening of congenital adrenal hyperplasia

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Background: Time frame for follow-up an infant with positive newborn screening (NBS) for congenital adrenal hyperplasia (CAH) is generally short. Since July 2006, CAH has been added into Taiwan NBS. Six centers located at different parts of Taiwan are responsible for confirmation of diagnosis and treatment. There have been 1,800,940 newborns screened, with 116 confirmed to have CAH. The coordinators at the confirmatory center are the first person who phone and discuss positive screening results to the parents. In Chinese tradition, infants are kept at home during the first month of life; thus, parents are reluctant to bring their child out for follow-up as instructed.

Methods: During January 2003–present, the author as a coordinator, has experienced in contacting 60 families with positive CAH screening. Here, the author's experiences were reported.

Results: The objectives/issues discussed during the first

call to the parents were as follow: (I) to obtain clinical data of the infants, including general appearance, movement, feeding, sucking, skin color specially over the genital area; (II) to warn the parents about possible serious symptoms related to CAH; (III) to educate the parents regarding urgent/emergent symptoms requiring to bring the babies to the medical center, emergency contact; (IV) to arrange clinical appointment with CAH specialist. If the family did not show up, repeat phone calls and rescheduling were followed. Some parents persistently missed the appointment, in such case the coordinator may reschedule to the birth hospitals/local public health center. Furthermore, some parents perceived that their child appeared healthy and refused further testing. Additional problems were the following: (I) distance and commuting time from home to the confirmatory center; (II) availability of CAH specialist; (III) difficulty in arrangement clinical follow up during long holidays and vacation of physician involved.

Conclusions: These experiences can be used for improvement of coordination, tracking for follow-up and management of the Taiwan NBS system.

Keywords: Newborn screening system (NBS); congenital adrenal hyperplasia (CAH); Taiwan; coordination

doi: 10.21037/atm.2017.s113

Cite this abstract as: Chien S. Experiences from coordinating parents whose child with positive results of newborn screening of congenital adrenal hyperplasia. *Ann Transl Med* 2017;5(Suppl 2):AB113. doi: 10.21037/atm.2017.s113