ENDOCRINE CONDITIONS

Caring for Children with Endocrine Conditions in a Community Program

Unified Referral and Intake System (URIS)
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INTRODUCTION

The Unified Referral and Intake System (URIS) is a joint collaboration among various government departments, health service organizations, school divisions and child caring organizations. URIS supports community programs in the care of children with specific health care needs. Community programs that are eligible for URIS support include schools, licensed child care facilities and respite service.

URIS provides a standard means of classifying the complexity of health care needs and establishes the level of qualification required by personnel to support children with these health care needs. Health care needs that are classified as 'Group B' can be delegated to non-health care personnel who receive training and monitoring by a registered nurse. For children with 'Group B' health needs (e.g. endocrine conditions), the nurse provides the following support:

- develops and maintains a written health care plan;
- provides training to community program personnel that are responsible for the child; and
- monitors community program personnel that receive training

This document provides standard clinical information that is relevant to the care of children with endocrine conditions during attendance in a community program setting. Supplemental documents are also provided to assist the nurse in the development of health care plans and training and monitoring of community program personnel.

CLINICAL INFORMATION

The following information is considered best practice in community program settings and is the basis for all endocrine information contained in this document and its supplements.

Endocrine System

The pituitary gland is located at the base of the brain and is often referred to as the "master gland". It controls several other hormone glands including the thyroid and adrenal glands. The pituitary gland produces hormones that are important for normal growth and puberty.

- Adrenocorticotropic hormone (ACTH) stimulates the adrenal glands to produce cortisol, aldosterone and androgens which are essential for bodily functions.
    - Cortisol modifies the body's response to inflammation, stimulates the liver to raise blood glucose and helps control blood pressure. It assists the body in coping with physical stress, illness and injury. A deficiency of cortisol can be life threatening if not managed properly.
    - Aldosterone is a hormone that helps regulates salt and water levels in the body and regulates blood volume and blood pressure.
    - Androgens are weak male sex hormones that are present in both sexes. They are important for sexual maturity.
- Growth hormone (GH) is important for growth of bone and body tissue, muscle development and sugar and fat metabolism.
- Thyroid stimulating hormone (TSH) stimulates the thyroid gland and affects the body's metabolism, body and brain growth and development and affects the function of the heart, kidney, liver and skin.
- Luteinizing hormone (LH) and follicle stimulating hormone (FSH) stimulate the sex organs to produce puberty hormones. A lack of these hormones prevents the body from developing physical maturity.
- Antidiuretic hormone (ADH) helps the body to maintain water balance.

Hypopituitarism

Hypopituitarism is a decrease or absence of one or more pituitary hormones. It can be congenital (present at birth) or acquired. Congenital hypopituitarism usually occurs as a result of missing or malformed structures in the middle of the brain (e.g. septo-optic dysplasia). Acquired hypopituitarism can result from tumors, infection, head injury, radiation treatment for cancer, surgery to the brain and diseases such as histiocytosis or iron overload. In some cases, hypopituitarism has no known cause.

Some children with hypopituitarism may experience hypoglycemia. In such situations, the community program should be aware of the signs of hypoglycemia and how to respond (see page 11). The child may bring a blood glucose monitor to the community program to check their blood glucose level when experiencing signs of hypoglycemia. They do not require routine blood glucose monitoring.

Adrenal Insufficiency

Adrenal insufficiency can have many causes. These are conditions in which the adrenal glands do not produce the right amount of important hormones to meet the body's needs. These hormones include cortisol and aldosterone. These hormones help maintain blood pressure and blood glucose as well as maintain salt and water balance. A lack of cortisol or aldosterone lowers blood pressure and blood glucose levels which can lead to acute adrenal insufficiency.

The treatment for adrenal insufficiency is oral cortisol (i.e. hydrocortisone) or other corticosteroid (e.g. prednisolone) which is taken 2 to 3 times daily, usually at home. A child with adrenal insufficiency may require a regular dose of hydrocortisone in the afternoon which may need to be administered by community program personnel. When the child is experiencing significant physical stress such as illness or injury, a stress dose of cortisol is also required (see page 10). The stress dose is two to three times higher than the regular dose of cortisol.

Primary adrenal insufficiency

Primary adrenal insufficiency (AI) results from a loss of cortisol and/or aldosterone due to the near total or total dysfunction of both adrenal glands. The most common cause of primary AI is an autoimmune disease (Addison's disease). Other causes include bleeding in the adrenal glands, infection, genetic diseases and surgical removal of the adrenal glands or an inherited condition called congenital adrenal hyperplasia (see below).

Symptoms of primary AI are chronic and steadily worsening fatigue, loss of appetite and weight loss, nausea, vomiting, diarrhea and hyperpigmentation. A person with primary AI may have low blood pressure that worsens when standing which can result in lightheadedness. The muscles are weak and may go into spasm. Because of salt loss, a craving for salty foods may occur. The increase in ACTH due to the loss of cortisol can produce a darkening of the skin that may look like a tan.

Some children with primary AI may also experience hypoglycemia. In such situations, the community program should be aware of the signs of hypoglycemia and how to respond (see page 10). The child may bring a blood glucose monitor to the community program to check their blood glucose level when experiencing signs of hypoglycemia. They do not require routine blood glucose monitoring.

Congenital adrenal hyperplasia (CAH)

CAH is an inherited form of primary adrenal insufficiency in which the adrenal glands do not work properly. The most common cause of CAH is a lack of the enzyme 21-hydroxylase. When this enzyme is missing or functioning poorly, the body cannot make adequate amounts of cortisol and aldosterone. CAH can be severe (classic) or mild (nonclassic).

With *classic salt-wasting CAH*, the adrenal glands do not make enough cortisol and aldosterone. With *classic non-salt wasting CAH*, the adrenal glands make enough aldosterone but not enough cortisol.

Some children with CAH may also experience hypoglycemia. In such situations, the community program should know the signs of hypoglycemia and how to respond (see page 11). The child may bring a blood glucose monitor to the community program to check their blood glucose level when experiencing signs of hypoglycemia. They do not require routine blood glucose monitoring.

With *non classic CAH*, a partial enzyme is deficient. There is some cortisol production, normal aldosterone production and lower levels of adrenal androgens. Signs of non classic CAH include early development of armpit and pubic hair, rapid growth during childhood and early or severe acne. Some people may need a low dose of cortisol but are not at risk for acute adrenal insufficiency. Because non classic CAH does not put a child at risk for a medical emergency this condition is not eligible for URIS Group B support.

Secondary adrenal insufficiency (AI)

With secondary adrenal insufficiency (AI), the pituitary gland does not send ACTH to the adrenal glands and therefore no cortisol is produced. Causes of secondary AI may be permanent including hormone problems present at birth, tumors or infections in the pituitary, surgical removal of tumors in or around the pituitary gland or radiation damage to the pituitary.

A temporary form of secondary adrenal insufficiency may occur when a person who has been taking corticosteroids (e.g. prednisone) for a non endocrine disease (e.g. Crohn's disease) for a long time stops taking the medication. When a person takes corticosteroids for prolonged periods, the adrenal glands produce less of their natural hormones. Once the prescription steroids are discontinued, the adrenal glands may be slow to restart production of cortisol. To give the adrenal glands time to regain function and prevent adrenal insufficiency, corticosteroid medication is reduced gradually. In some cases daily doses and/or stress doses of hydrocortisone will be used until the hypothalamic-adrenal axis has completely regained function.

Some children with secondary AI may also be at risk for hypoglycemia. In such situations, the community program should be aware of the signs of hypoglycemia and how to respond (see page 10). The child may bring a blood glucose monitor to the community program to check their blood glucose level when experiencing signs of hypoglycemia. They do not require routine blood glucose monitoring.

Hyperinsulinism

Congenital hyperinsulinism (HI) is a cause of severe, persistent hypoglycemia in newborn babies and children. With HI, the pancreas makes excess amounts of insulin. As a result, the child can develop hypoglycemia at any time but particularly when fasting. Unlike other hypoglycemia-causing conditions in which alternative fuels, such

as ketones or lactate, may be available for the brain during periods of hypoglycemia, HI prevents the production of these fuels and leaves the brain without a source of energy. Brain damage can occur in children with HI if their condition is not recognized or if fast acting sugar is ineffective in treating hypoglycemia.

Children with hyperinsulinism will check their blood glucose on a daily basis, at home. If the child's medication is being adjusted, the parent/guardian may request regular blood glucose monitoring at the community program for a short period of time. It is recommended that blood glucose monitoring occurs at the community program when the child is showing signs of hypoglycemia. Medication for hyperinsulinism is usually given every 8 hours therefore can typically be given at home.

Diabetes insipidus

Diabetes insipidus is caused by a deficiency of the antidiuretic hormone (ADH). ADH helps the body keep water in balance. If ADH is low, the kidneys cannot hold onto water. Diabetes insipidus is characterized by frequent thirst and the excretion of large amounts of urine.

Diabetes insipidus is treated with replacing the missing ADH with a synthetic form called Desmopressin (DDAVP). DDAVP is typically administered at home. It can be administered by mouth, nasal spray or injection. Community program personnel may administer DDAVP by mouth or nasal spray only. If a DDAVP injection is required, it must be administered by the parent/guardian or emergency contact.

If a child's DDAVP medication was not taken or not absorbed properly, the child will experience frequent thirst and urination (every 30-60 minutes). If the child experiences these symptoms, the following steps are implemented.

1. Contact the parent/guardian to determine if a dose of DDAVP is required as it depends on when the next regular dose is scheduled.
2. If the parent/guardian cannot be contacted, no further action is required. This is NOT a medical emergency. Therefore, 911/EMS is not required if DDAVP is not administered.

A child with diabetes insipidus requires unlimited access to the washroom and water. Although rare, a child with diabetes insipidus is at risk for seizures if their sodium levels become extremely low. If a child experiences a seizure or becomes unconscious, 911/EMS must be initiated immediately.

Other endocrine conditions

The following endocrine conditions do not put a child at risk for a medical emergency and therefore are not eligible for URIS 'Group B' support.

Hyperthyroidism

Hyperthyroidism is a condition in which the body makes more thyroid hormone than it needs. Too much thyroid hormone makes the body speed up its activities including heart rate, blood pressure and metabolism. The most common type of hyperthyroidism is called Graves' disease. With Graves' disease, the immune system produces antibodies that bind to the thyroid gland, causing it to make and release too much thyroid hormone. Treatment may include anti-thyroid drugs, radioactive iodine and/or surgery. The child may also be prescribed a beta blocker to slow down the heart rate. Medication can typically be given at home. It is well known that hyperthyroidism can affect concentration and academic performance until diagnosed and adequately controlled. Because uncontrolled hyperthyroidism may also cause elevated heart rates it is recommended that the child is excluded from strenuous physical activity until the condition is adequately treated (about 4 weeks from starting medication).

Hypothyroidism

A lack of thyroid hormones (hypothyroidism) can result in poor growth, slowing of mental and muscle function, weight gain, feeling cold and other symptoms. Hypothyroidism is treated with thyroid medication taken daily. Medication can typically be given at home.

Cushing's Syndrome

When too much cortisol is produced in the adrenal glands or an excess of cortisol is taken to treat other diseases, significant changes occur in the tissues and organs of the body. All of these effects together are called Cushing's Syndrome. Causes of Cushing's Syndrome include tumors in the pituitary or adrenal glands or taking larger doses of corticosteroids to treat other medical conditions (e.g. Crohn's). Symptoms usually include fatigue, weakness, depression, mood swings, increased thirst and urination and lack of menstrual periods in women.

Deficiencies in growth hormone

Deficiencies in growth hormone (GH), thyroid stimulating hormone (TSH), luteinizing hormone (LH) and follicle stimulating hormone (FSH) typically do not put a child at risk for a medical emergency. Therefore, 'URIS Group B' support for such conditions is not required.

Adrenal insufficiency

When a child experiences physical stress

If a child with adrenal insufficiency experiences physical stress and is not well enough to remain at the community program (e.g. illness, infection, significant injury), a stress dose of cortisol is required.

Signs of physical stress

- **Nausea**
- **Vomiting**
- Fever
- Cold clammy skin
- Pale face
- Dark circles under the eyes
- Unexplained dizziness
- Lethargy/weakness
- Confusion

If the child experiences any of the signs of physical stress listed above and is not well enough to remain at the community program, the following steps are implemented.

1. Administer the stress dose, if available.
2. Stay with the child.
3. Notify the parent/guardian and make arrangements for the child to be picked up.
4. If the parent/guardian or alternate emergency contact cannot be reached to pick up the child and the child's physical symptoms persist for 30 minutes, call 911/ EMS.

A child that is experiencing physical stress should not remain at the community program, even if the stress dose is administered. The priority is for the parent/guardian to be notified and take the child home. Do not send the child home on their own or on the bus if they are experiencing physical stress.

Acute adrenal insufficiency

Symptoms of acute adrenal insufficiency include severe vomiting, seizures and loss of consciousness. The treatment for acute adrenal insufficiency is administration of cortisol by intramuscular injection. Community program personnel cannot administer injections. Arrangements may be made for the injectable medication to be stored at the community program to be administered by the parent/guardian or alternate emergency contact. This is recommended in situations where EMS response time is prolonged (e.g. remote location). Emergency medical personnel may not be able to administer the injection until arrival at hospital.

If the child experiences any signs of acute adrenal insufficiency including continuous vomiting, seizures and/or loss of consciousness, the following steps are implemented.

1. Call 911/EMS.
2. Administer the oral stress dose, if available and child is conscious.
3. Notify the parent or guardian.
4. Stay with the child until EMS arrives.

Hypoglycemia

Children with endocrine conditions including adrenal insufficiency, congenital adrenal hyperplasia, hyperinsulinism and growth hormone deficiencies are at risk for hypoglycemia.

Signs of hypoglycemia

- Cold, clammy or sweaty skin
- Shakiness, lack of coordination
- Irritable, hostile, poor behavior
- Tired
- Sudden moodiness or behavior change
- Difficulty concentrating, confusion
- Staggering gait
- Child may complain of
  - hunger
  - nervousness
  - excessive hunger
  - headache
  - blurred vision
  - dizziness
  - abdominal pain or nausea

If the child has a blood glucose monitor available and/or has a history of hypoglycemia and is showing signs of hypoglycemia

1. Check blood glucose, if monitor is available and time permits.
2. If blood glucose is less than 4 mmol/L* and/or child is showing signs of hypoglycemia, have child eat a fast acting sugar (15 grams of carbohydrates).

   Examples of fast acting sugar
   - 1/2 cup of juice or regular soft drink
   - 3 tsp or 3 packets of table sugar
   - 1 tbsp honey
   - 6 life savers
   - 4 Dextrose tablets
3. Wait 10-15 minutes and check blood glucose again (if monitor is available). If blood glucose is less than 4 mmol/L and/or child is still showing signs of hypoglycemia, have child eat a second fast acting sugar.

4. Wait 10-15 minutes and check blood glucose again (if monitor is available). If blood glucose is less than 4 mmol/L and/or child is still showing signs of hypoglycemia, have child eat a third fast acting sugar and contact the parent/guardian.
5. If unable to contact parent/guardian or alternate emergency contact, call 911/EMS.

IF IN DOUBT, TREAT!

DO NOT LEAVE CHILD ALONE for at least 30 minutes after the treatment of hypoglycemia.

*For some children, the pre-determined glucose level for hypoglycemia may be less than 4 mmol/L, as determined by the endocrinologist.

If severe hypoglycemia occurs, the child will have a seizure or become unconscious. If this occurs, the following steps are implemented.

1. Call 911/EMS.
2. Place child in a side lying position.
3. Notify parent/guardian.

DO NOT give food or drink.
DO NOT leave the child alone.

HEALTH CARE PLAN

When a community program receives URIS Group B support for children with URIS 'Group B' health care needs, a written health care plan is developed and maintained by a registered nurse on at least an annual basis. The development and implementation of the health care plan should reflect the principles of inclusion, normalization and independence.

- A child with an endocrine condition is foremost a child within a family, child-care facility, classroom or other community program
- The environment should be changed to support the child, not the child changed to suit the environment
- Interventions should be as non-intrusive as possible and be delivered in a manner that respects the child's dignity and privacy as well as the normal routines and patterns of the community program
- The parent/guardian and child have rights and obligations and should be encouraged to actively participate in decisions affecting them.

Consultation with the parent/guardian and community program is required to develop a health care plan that is relevant to the child's needs and appropriate within the community program setting. For children that receive medical care through the Section of Pediatric Endocrinology and Metabolism at Children's Hospital HSC Winnipeg, the endocrinologist provides the family with a written emergency plan for home/school/child care facility use. It is expected that the health care plan developed by the URIS nurse is consistent with the endocrinologist's written recommendations. For some children, the management of their endocrine condition may be complex and consultation with the endocrinologists may be required to ensure appropriate care is provided within the community program setting.

When a child has multiple health care needs, all relevant information should be integrated into one comprehensive health care plan. The format should use plain language and include information that is required to manage the child's endocrine condition in a safe and appropriately manner during attendance at the community program

The health care plan should be kept in a location that is secure and accessible. Community program personnel that are responsible for the child should be aware of its location. The health care plan and emergency medication should accompany the child on excursions outside the facility.

Adrenal Insufficiency health care plan

The following information is required in the health care plan developed for children requiring daily replacement of steroids to treat endocrine conditions including primary adrenal insufficiency (Addison's disease and classic CAH) and secondary adrenal insufficiency (AI). The *Adrenal Insufficiency Health Care Plan* contains this information and is included as a supplement to this document.

Demographic information

- Child's name
- Birth date
- Community program name
- Parent(s)/guardian name and phone number(s)
- Alternate emergency contact name and phone number(s)
- Endocrinologist name and phone number
- Family physician/pediatrician name and phone number

Medical information

- Medical diagnoses and other relevant conditions
- Known allergies
- Availability of Medic-Alert® identification
- Prescribed medications
    - If medication is administered at home, the name of medication is required.
    - If medication is administered at the community program, the medication name, dose, location, time and route of administration is required. Community programs that have an internal policy for administration of medication may have already obtained this information.

Adrenal Insufficiency information

- History (e.g. when diagnosed, history, current status)
- Stress dose information
    - Child’s ability to recognize & respond to need for stress dose
    - Name, route, dose and location of medication if administered by community program personnel

Potential problems and emergency situations

- Physical stress
- Acute adrenal insufficiency
- Hypoglycemia, if child has blood glucose monitor at the community program and/or history of hypoglycemia

Documentation

- Template for recording interventions and actions performed by the nurse and/or community program personnel (e.g. communication, actions taken)
- Signatures & dates
    - Nurse signature & date(s) of health care plan development/review
    - Parent/guardian signature & date

Hyperinsulinism health care plan

The following information is required in the health care plan developed for children with hyperinsulinism. The *Hyperinsulinism Health Care Plan* contains this information and is included as a supplement to this document.

Demographic information

- Child's name
- Birth date
- Community program name
- Parent(s)/guardian name and phone number(s)
- Alternate emergency contact name and phone number(s)
- Endocrinologist name and phone number
- Family physician/pediatrician name and phone number

Medical information

- Medical diagnoses and other relevant conditions
- Known allergies
- Availability of Medic-Alert® identification
- Prescribed medications
    - If medication is administered at home, the name of medication is required.
    - If medication is administered at the community program, drug name, dose, location, time and route of administration is required

Hyperinsulinism information

- History (e.g. when diagnosed, history, current status, ability to recognize hypoglycemia)
- Type and location of fast acting sugars
- Location of glucagon, if stored at the community program

Potential problems and emergency situations

- Hypoglycemia

Documentation

- Template for recording interventions and actions performed by the nurse and/or community program personnel (e.g. communication, actions taken)
- Signatures & dates
    - Nurse signature & date(s) of health care plan development/review
    - Parent/guardian signature & date

Diabetes insipidus health care plan

The following information is required in the health care plan developed for children with diabetes insipidus. The *Diabetes Insipidus Health Care Plan* contains this information and is included as a supplement to this document.

Demographic information

- Child's name
- Birth date
- Community program name
- Parent(s)/guardian name and phone number(s)
- Alternate emergency contact name and phone number(s)
- Endocrinologist name and phone number
- Family physician/pediatrician name and phone number

Medical information

- Medical diagnoses and other relevant conditions
- Known allergies
- Availability of Medic-Alert® identification
- Prescribed medications
    - If medication is administered at home, the name of medication is required.
    - If medication is administered at the community program, drug name, dose, location, time and route of administration is required

Diabetes insipidus information

- History (e.g. when diagnosed, history, current status)
- DDAVP information
    - Name, route, dose and location of medication
    - Child’s ability to recognize & respond to need for DDAVP

Potential problems and emergency situations

- When child experiences extreme thirst or urination
- When child has a seizure or becomes unconscious

Documentation

- Template for recording interventions and actions performed by the nurse and/or community program personnel (e.g. communication, actions taken)
- Signatures & dates
    - Nurse signature & date(s) of health care plan development/review
    - Parent/guardian signature & date

TRAINING

When a community program receives URIS 'Group B' support, training is provided to community program personnel by a registered nurse. Training is provided on at least an annual basis. The training of community program personnel should reflect the principles of adult learning.

- The learning needs of participants should be identified and integrated into the training session
- Information should be applicable to the participants' responsibilities and focus on what is most useful to them
- Adults have accumulated a foundation of life experiences and knowledge and need to connect learning to this knowledge base
- An organized training session with clearly defined elements assists participants in identifying and attaining learning goals

It is recommended that all community program personnel that may be responsible for a child with an endocrine condition attend the training session. As an example, community program personnel that may be responsible for a child with an endocrine condition in a school may include teachers, educational assistants, school administrators, office staff, substitute teachers, bus drivers and lunch room supervisors. The community program is responsible to ensure personnel that may be responsible for a child with an endocrine condition attend the training session. It is required to keep a written record that indicates community program personnel in attendance and date that training occurred.

Adequate time should be scheduled for training to ensure community program personnel obtain the knowledge and skill necessary to safely respond to the needs of children who have an endocrine condition within their facility. The amount of time required to train community program personnel will vary depending on factors such as the existing knowledge of community program personnel, number of persons attending the training session and the format of training resources used (e.g. PowerPoint, Worksheet).

To ensure service is provided in an efficient manner, training should be scheduled when all community program personnel that may be responsible for the child can attend. If an adequate number of community program personnel did not attend the training session, additional training should be scheduled. If subsequent training sessions are also poorly attended, alternate strategies should be discussed with the community program to ensure training is provided in an efficient manner. If the issue remains unresolved, the URIS Provincial Coordinator and/or relevant agency (e.g. school division, Provincial Day Care, Family Services) may need to become involved.

When the community program has not received training, a child with an endocrine condition may attend the community program. In such situations, the community program's standard policy for medical emergencies is implemented, as required.

Content

The following clinical information and child specific information is included in the training session.

Standard clinical information

- Endocrine system
- Endocrine condition(s) relevant to child
- Adrenal insufficiency, if relevant to child
- Hypoglycemia, if relevant to child
- Diabetes insipidus, if relevant to child

Child specific information

- Type of endocrine condition
- Location of emergency medication (e.g. cortisol, fast acting sugar, DDAVP)
- Additional information specific to child

Training Resources

The following resources may be used for training purposes and are included as supplements to this document. If alternate resources are used, it is the responsibility of the nurse to ensure its content is consistent with the clinical information included in this document.

- *Endocrine Condition PowerPoint* includes information that is relevant to all endocrine conditions.

MONITORING

Monitoring of trained community program personnel by a nurse is required to ensure that the knowledge and skill necessary to safely care for children with an endocrine condition has been retained. Monitoring is required on at least an annual basis.

The frequency and timing of monitoring is based on the professional judgment of the nurse as well as the complexity of information taught, maturational issues and the skill demonstrated by community program personnel. A strategy for monitoring community program personnel may be to complete the *Endocrine Condition Training Session Evaluation Form* after attending the training session which is included as a supplement to this document.

The community program may also request additional monitoring if personnel have questions/concerns and/or require additional support to ensure they are responding to the child's needs in a safe and appropriate manner.

REFERENCES

Arafah, Baha M. & Auchus, Richard J. (2010). **Adrenal Insufficiency Fact Sheet.** Hormone Health Network**.**

Arafah, B.M. & Auchus, RIchard J. (2010). **Adrenal Insufficiency Fact Sheet.** Hormone Health Network website.

Donohoue, P.A., Poth, M. & Speiser, P.W. (2010). **Congenital Adrenal Hyperplasia Fact Sheet.** Hormone Health Network website.

Findling, J.A. & Young, W.F. Jr. (2010). **Cushing's Syndrome Fact Sheet.** Hormone Health Network website.

Findling, J.A., Nieman, L. & Vigersky, R. (2010). **Diagnosis of Cushing Syndrome Patient Guide.** Hormone Health Network website.

Oberfield, S.E. & Speiser, P.W. (2010). **COngenital Adrenal Hyperplasia Patient Guide.** Hormone Health Network website.

National Adrenal Diseases Foundation website

National Endocrine and Metabolic Diseases Information Service (NEMDIS) website. **Adrenal Insufficiency and Addison's Disease**

RESOURCES

The following list includes resources that may be relevant to community programs in the care of children with endocrine conditions. The purpose of these agencies/organizations may not be consistent with the purpose and content of this manual.

National Adrenal Diseases Foundation
www.nadf.us

National Endocrine and Metabolic Diseases Information Service (NEMDIS)
www.endocrine.niddk.nih.gov

The Magic Foundation
www.magicfoundation.org

CARES Foundation
www.caresfoundation.org