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Life After Hospital Discharge: Caring for Pediatric Patients Receiving Nutrition Support in the Home Care Setting

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Abstract

The pediatric registered dietitian nutritionist (RDN) in the home care setting is a relatively unique and rare position. However, there is a growing need for home care pediatric RDNs, as the use of home enteral nutrition (HEN) and home parenteral nutrition (HPN) in the pediatric population is becoming more frequent.

The purpose of this article is to provide an overview of the pediatric RDN in the home care setting, reviewing detailed day-to-day responsibilities, coordination of care, patient population, special considerations, and a call to action. There is minimal research surrounding the role of the pediatric home care RDN, resulting in limited guidance on standards of practice. Collaboration is imperative between the hospital and home care teams during the transition from hospital to home. Special considerations such as socioeconomic status, education level, and communication barriers should be considered and addressed.

Introduction

Enteral nutrition was first delivered to newborns and preterm infants during the 1970s.¹ Since then, enteral and parenteral

nutrition have evolved into a means for supporting the growth and overall nutrition status of pediatric patients in the hospital and home setting. The prevalence of home enteral nutrition (HEN) and home parenteral nutrition (HPN) in the pediatric population is difficult to quantify due to a lack of data. However, one study determined 4 in 100,000 children require enteral nutrition.² Despite the limited data, the survival rate of preterm infants or children with complex health-care needs is increasing, resulting in about 10 million children in the United States with special health-care needs.¹ This information could lead to the conclusion that HEN and HPN are also increasing since children with special health-care needs often require these therapies.

The home care registered dietitian nutritionist (RDN) is a vital aspect in the success of patients receiving HEN and/or HPN. The responsibilities of the home care RDN are continually evolving to support the ever-changing patient population. Current roles include education on HEN or HPN, troubleshooting, ensuring adequate growth, preventing malnutrition, and simply offering support.

There are many home care companies that provide different services, as shown in Table 1. Home care companies vary in their ability to provide the aforementioned services and products. This may result in patients needing services from multiple companies. Unfortunately, there are no requirements or standards for home care

Table 1. Types of home care companies

Durable medical equipment (DME) company: Provides medical supplies such as wheelchairs, oxygen, enteral supplies, etc.

Home medical equipment (HME) company: Provides services and training associated with the medial supply

Home infusion company: Delivers intravenous therapy in the home

Home nursing company: Provides extended-hour nursing care at home, school, or work

Skilled nursing company: Provides in-home, intermittent nursing visits to check weight, blood pressure, wound status, etc.

companies to specialize in pediatric care or employ RDNs who specialize in pediatric nutrition. For this reason, it's important home care companies are thoroughly investigated to ensure appropriate care can be provided for a medically complex pediatric patient.

This article will outline current literature and practices performed by the authors as well as a call to action on how to improve communication, ultimately leading to improved patient outcomes.

Patient Population

The pediatric patient population in the home care setting is extremely variable in terms of diagnosis and complexity. These inconsistencies make each child's situation unique, and the plan of care must be tailored to meet individual needs.

Patients typically range in age from 1 to 2 months up to 20 to 30 years old. Many have common diagnoses, such as trisomy 21, cerebral palsy, or prematurity, while others have less common diagnoses, including Moebius syndrome, trisomy 9, short bowel syndrome, or congenital central hypoventilation syndrome. The care plan for a child with a rare diagnosis can be more difficult to outline due to limited information on the diagnosis, growth standards, effective interventions, or overall outcomes and life expectancy.

The patient's diagnosis (or diagnoses) ultimately influences his or her need for complex and life-sustaining medical treatments, including but not limited to: tracheostomy with or without ventilator support, HEN, HPN, or enzyme replacement therapy. In addition, many patients require an extensive medication list, therapies, bowel programs, and constant attention to ensure successful medical outcomes.

High-Needs Patients

A high-needs patient may require weekly or even daily attention in the form of nutrition support changes, anthropometric assessment, communication with the caregiver, or coordination of care with

Table 2. Considerations when patients transfer care between hospital and home care registered dietitian nutritionists

- Overall nutrition care
- History of formulas attempted with success or failure
- Review of pertinent social situations
- Growth and formula goals
- Where family is obtaining formula, such as WIC, DME, or purchasing out of pocket
- Whether paperwork is complete in order for family to obtain formula
- Caregiver preferences regarding formula, feeding plans, or communication method
- Faxing the patient's growth chart and most recent nutrition assessment to the new dietitian

other medical providers. Based on anecdotal experience, high-needs patients require a home nutrition visit by the RDN every three to four months.

High-tech patients, or children relying on life-sustaining technology, tend to be high-needs patients. High-tech patients frequently have a complex medical diagnosis, making them prone to intolerances to nutrition support, such as reflux, nausea, vomiting, constipation, diarrhea, or poor or excessive growth. Their medical status can change frequently, which influences nutrition.

Premature infants may also become high-needs patients due to rapid growth, which requires frequent weight checks and nutrition support changes. In addition, non-English-speaking families or children living in a difficult social environment may become high-needs patients. These situations can make it more challenging to communicate and obtain information.

Low-Needs Patients

Based on anecdotal experience, low-needs patients typically require a home nutrition visit by the RDN every 6 to 12 months. Low-needs patients are normally older children or those only receiving HEN.

Transition from Hospital to Home

One of the primary goals during the transition from hospital to home is a seamless continuation of care to prevent readmission to the hospital. This is

especially important for the pediatric patient receiving nutrition support. Table 2 reviews suggested items of discussion when transferring patients from hospital to home or vice versa.

The first step in the transition from hospital to home is to ensure the patient is medically stable and tolerating their nutrition support plan.^{1,3} It is important to limit changes prior to discharge and address any intolerance symptoms.¹ The home environment should also be assessed for safety.^{1,4}

Next, the emphasis should be centered on thorough training for caregivers on HEN and HPN before discharge.^{1,3-5} Education should include safe practices for storage, preparation, and administration, as well as potential risk factors and available resources to help resolve complications. Ideally, caregivers should receive multiple training sessions and have access to a variety of educational resources (written, video, and/or demonstration) to ensure their learning needs are successfully met.⁴ Sevilla and McElhanon¹ stress the importance of caregivers staying overnight for one to two days to perform all needed medical cares before discharging home.

In addition, organizing a multidisciplinary care conference between the hospital and home care providers at the time of discharge is important, especially for patients receiving HPN.⁴ Depending on the patient's needs, the care conference

should include the inpatient provider, primary provider (including any specialist the patient requires), respiratory therapist, nurse, dietitian, home care nurse, home infusion nurse, family, and anyone else involved in the patient's care. The discharge care conference allows for an overview of the patient's medical history and future goals as well as opens a line of communication between care providers. It also fosters an environment in which the family can ask questions and become acquainted with the provider they will contact for certain issues.⁴ It is essential that the hospital and home care teams communicate clearly and accurately before discharge to ensure all parties understand the regimens for HEN or HPN.^{4,5}

At home, the family should have access to 24-hour on-call services to ask questions or troubleshoot issues. Consistent follow-up and monitoring should be established by the home care company to guarantee appropriate medical care is provided and safe practices are continued in the home.^{4,5}

Unfortunately, the transition from hospital to home does not always entail the ideal discharge process. There are times when the discharge care conference does not occur or all parties involved are not included. On occasion, the home care company is notified as few as 12–24 hours before the patient's discharge, making caregiver education last minute or nonexistent. Some families are discharged home before the inpatient dietitian can provide instruction on the patient's nutrition support regimen. Suffice it to say, the communication and coordination of care between the hospital and home care company has areas for improvement.

Day-to-Day Responsibilities

Standard of Practice

Summarized in Table 3 are the standards of practice developed by the American Society for Parenteral and Enteral Nutrition (ASPEN) for nutrition support patients in the home care setting.⁶

These standards of practice should be applied and implemented by the home care company. This can be difficult due to a lack of company resources, reimbursement, or trained clinicians. Additionally, poor follow-up from family can hinder the ability of the home care company to offer appropriate, consistent, and safe care. However, home care companies should make every effort to implement these standards of practice.

Home Visit

Home visits are an important aspect of home care. They offer an opportunity to assess the patient in his or her daily environment and build a relationship with the patient and caregiver(s). In addition, the home visit allows the clinician to complete a comprehensive nutrition assessment, assess for malnutrition, and perform a nutrition-focused physical assessment. This is crucial when caring for the pediatric population because growth charts and assessments conducted over the phone can only portray a limited picture of the

child's nutrition status. Unfortunately, there is no data outlining if RDN home visits are a standard of practice or commonly performed. See Table 4 for tips on how to complete a successful home visit.

Electronic health records (EHR) are utilized for many aspects of home care nutrition. The EHR houses pertinent information, including external medical records, orders, supply and shipment history, demographic information, and insurance providers. This information must be taken into consideration when preparing for home visits. Upon completion of the home visit, the comprehensive nutrition assessment is documented in the EHR and shared with the interdisciplinary team that is associated with the patient. The multidisciplinary team may be located within the company or externally.

The home care RDN is required to obtain an order from the provider before any changes are initiated. Many times these orders are sent to the provider through

Table 3. ASPEN standards of practice for home nutrition support patients

1. Provide a multidisciplinary approach that includes (but is not limited to) the referring medical providers, the primary physician with expertise in HEN and HPN, and the home care RDN, nurse, and pharmacist.
2. Establish policies and procedures outlining provider roles, criteria for patient eligibility, follow-up frequency, patient and caregiver education, and safety guidelines for HEN or HPN.
3. Utilize medical records to document confidential patient information and provide patient access to the care facility's 24-hour, on-call services.
4. Complete a nutrition evaluation at the time of admission to determine malnourished or nutritionally at-risk patients.
5. Execute a comprehensive nutrition assessment for patients identified as nutritionally at-risk or receiving HEN or HPN.
6. Develop the patient's nutrition plan of care, outlining goals and expectations of the patient, caregiver, and other medical providers, and ensure the patient has access to and reimbursement for the appropriate interventions.
7. Implement the nutrition plan of care, ensuring the ordering process is complete, education is provided to the patient or caregiver, and HEN or HPN is prepared, delivered, stored, and administered safely.
8. Outline an ongoing monitoring tool for the nutrition support team that documents progress and can be communicated easily to all providers involved.
9. Evaluate and update the nutrition plan of care to ensure optimal outcomes and determine the ability to transition to a different mode of nutrition support or oral intake.
10. Discontinue nutrition support therapy when appropriate.

fax and can take one to two weeks to return signed. This can cause a delay in interventions; however, planning ahead and anticipating changes can help shorten or diminish the delay. If the RDN feels comfortable, standard orders to adjust feedings to maintain appropriate growth can also be obtained as a means to apply changes immediately.

Home visits are considered the gold standard in home care nutrition; however, telemedicine is a potential new solution for assessing patients. Telemedicine could be utilized for patients located in rural locations where trained professionals may not be available.

HEN Patients

The nutrition assessment in the home care setting for a patient receiving HEN closely resembles the assessment completed in the acute care facility. Similar questions are asked about the patient's nutrition history, current HEN regimen, intolerances, hydration, and output adequacy. However, during the home visit, it is the RDN's responsibility to obtain an accurate

and up-to-date medication list, take anthropometrics, ensure the family has all the necessary supplies, and review safe practices for HEN storage, preparation, and administration. Familiarity with enteral supplies is important, as families often ask questions about venting the stomach, enteral tube extensions, feeding pumps, and feeding tubes.

Once the initial visit is complete, it is important the RDN receive a signed nutrition order from the following provider outlining the changes. HEN orders should include the formula type, concentration, daily amount, regimen, and route of administration. This order is then shared with all parties involved with that patient's care, including the home care nursing agency, family, the Special Supplemental Nutrition Program for Women, Infants, and Children (WIC), and the formula supply company.

Monitoring and evaluation can be conducted over the phone or via email. Anthropometric updates should be obtained by the home care nurse or family and assessed on a weekly or monthly

basis. Other updates on HEN tolerance or progress are obtained through the caregiver or home health nurse. HEN regimens are also adjusted to support appropriate growth of the patient. These changes can be made over the phone or during a follow-up visit.

Other tasks may include writing formula recipes or transition plans for scenarios such as infant to pediatric formula, elemental to semi-elemental formula, J-tube to G-tube feedings, or continuous to bolus feedings. In addition, the RDN is responsible for helping families navigate new trends, such as home or commercially blenderized formulas, ensuring nutrition needs are met and, ascertaining a safe care plan is in place.

HPN Patients

The nutrition assessment for a patient receiving HPN in the home care setting is very similar to the assessment completed in the acute care facility. The primary differences are the process for monitoring and the frequency of follow-up.

Once the initial home visit is complete, the home care RDN completes a weekly assessment for the patient based on updates from the family, infusion nurse, or nursing agency. Information on the patient's anthropometrics, oral regimen, intake and output record, labs, HEN progress, HPN tolerance, and any other pertinent updates are summarized in a written assessment.

The nutrition assessment is reviewed at a weekly multidisciplinary meeting to discuss HPN or HEN changes and the patient's overall plan of care. The multidisciplinary team typically includes the infusion nurse, home care nurse, pharmacist, dietitian, and ordering physician. The physician can provide the orders for changes during the meeting. However, if the physician is unable to attend the meeting, the nutrition assessment and recommendations are faxed to the physician for review, and orders are received via fax or over the phone.

Table 4. Tips for executing a successful home visit

- Verify time and location of the visit and ensure the patient will be present.
- Review with the family the duration of the visit and what will be discussed.
- Arrive on time and call the family if you will be late.
- Knocking is preferred over ringing the doorbell to avoid potentially waking a sleeping baby.
- Introduce yourself and remove your shoes before entering the living area.
- Discuss with the caregiver the information needed for the nutrition assessment, and ask to obtain anthropometrics and complete a physical assessment. Don't be afraid to take anthropometrics multiple times if they seem inaccurate.
- Ask open-ended and probing questions. If you are unable to obtain the needed information, ask the same question and phrase it differently each time.
 - What is the rate and total feeding time of your child's tube feeding each day?
 - How much formula do you provide your child each day?
 - How many containers of formula does your child use each day?
- Ask the family to show you how they mix the formula. This is especially useful for non-English-speaking families.
- Review your recommendations with the caregiver prior to contacting the provider to ensure they are in agreement.
- Review with the family the follow-up process and clearly outline the responsibilities of the family and the RDN for future monitoring.

(Continued on next page)

The RDN is responsible for updating the family and nursing agency on changes for the upcoming week. HPN is compounded, and a week's supply is sent to the family.

Benefits of Home Care

Home care offers the opportunity to form long-term relationships with families and provides insight into home environments. Having a better understanding of the patient's home life helps the clinician offer successful recommendations.

In addition, the patient's ability to receive medical care at home improves quality of life for both the patient and family. Rosen et al⁷ discovered patients receiving home nasogastric feedings had improved growth standard deviations between the time of discharge and a 6 to 12 week follow-up visit. The study demonstrated the positive impacts home nasogastric feedings have on short-term growth.⁷

Special Considerations

Special considerations fall into three broad categories: socioeconomic factors, communication, and literacy challenges. These categories overlap to impact the patient (Figure 1).

Socioeconomic Factors

There are multiple socioeconomic factors that need to be taken into consideration when evaluating HEN and HPN patients. Availability of financial resources can significantly inhibit an HEN or HPN patient from receiving appropriate nutrition. For the HEN patient,

insurance plans may not cover formula or feeding supplies, placing the burden on the family to purchase them. Standard formula can result in out-of-pocket expenses ranging from \$400 to \$600 per month. Depending on the HEN administration method, the cost of feeding bags, syringes, or a feeding pump can drive out-of-pocket costs even higher. An estimation of the annual out-of-pocket costs for the family of an HEN patient can range from \$8,000 to \$12,000.⁸ The HPN patient may experience similar issues. This financial burden forces some families to choose providing nutrition support for their child over paying other bills, such as phone service or electricity.

Literacy is another socioeconomic factor that needs to be considered when working with HEN and HPN patients, especially in the transition from hospital to home. In the United States, 18% of adults are illiterate, while 30% have less-than-proficient numeracy levels.⁹ Feeding regimens must be simplified for understanding when caregivers are unable to read. Written educational materials should predominantly rely on pictures for instruction rather than lengthy written explanations. This will assist with accuracy in the home setting.

Availability of basic household items should also be considered for the HEN or HPN patient. It is important to know whether caregivers have the appropriate tools to mix formula, including liquid and dry measuring cups and a container in which to mix formula. Additional items to check may include a scale to weigh the patient or a measuring tape to measure the patient's height. Further, it is crucial to assess the home environment to ensure electrical connection, refrigeration, telephone access, and clean water. A discussion with the caregiver should occur prior to discharge to determine which resources are needed for a safe transition home.

Social support and interactions are the last socioeconomic factors to keep in mind. Nelson et al discovered that although G-tube feedings eased caregiver burdens, they actually increased the intensity of

care needs and decreased parental sleep.¹⁰ Ensuring families have a good home support system and connecting them to additional support groups, such as the Oley Foundation, will help ease burdens brought on by HEN or HPN treatment. In fact, Chopy et al found that 100% of the surveyed participants wished they had found the Oley Foundation sooner, as it helped them feel they were not alone in dealing with HEN.¹¹

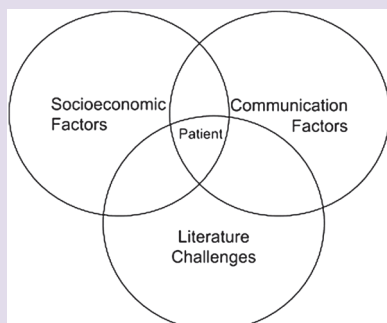
Social support groups can impact the family and caregiver in other ways as well. Caregivers often connect with families that have children with similar medical diagnoses via social media platforms, including Facebook, Twitter, or various blogs. Family members may share treatment options or tips for HEN that are not evidence-based nutrition. It is important for RDNs to understand family preferences and provide education as needed to ensure a safe care plan for the child.

Insurance Considerations

Insurance coverage of HEN or HPN varies according to policy. Insurance coverage of enteral formula is billed in units, where one unit is 100 calories. The Healthcare Common Procedure Coding System (HCPC) categorizes formula by protein type, fiber status, and other factors. Many insurance companies require prior authorization for formula or administration supplies. Prior authorization refers to a decision by the insurance company or plan that the formula or supplies are medically necessary. As a home care dietitian, you may be involved in writing statements of medical necessity. A statement of medical necessity identifies that the prescribed therapy is appropriate and not utilized as a convenience to alternative therapies.

Insurance coverage is also an issue for RDN visits to HEN and HPN patients. A recent position paper from the Academy of Nutrition and Dietetics explains that RDNs and dietetic technicians, registered (DTRs) are essential components of comprehensive care for pediatric patients with special health-care needs.¹² Although nutrition professionals are a valuable resource, most home care RDNs are rarely

Figure 1. Special considerations in home care nutrition combine to impact the patient



reimbursed unless they have affiliations with doctors or hospitals.

Anthropometrics

In the pediatric population, accurate anthropometrics can be difficult to achieve even by the most skilled clinicians. Children can be unpredictable and uncooperative with simple measurements, such as height and head circumference. Home care RDNs rely on family members, personal care attendants, or nurses to obtain follow-up measurements. This variability can pose difficulties, including inconsistent methods among caregivers, incorrect measurements, and ultimately incorrect analysis. Training caregivers to obtain accurate measurements is essential to the transition from hospital to home.

Communication

According to the Center for Immigration Status, 61.8 million Americans speak a language other than English in their home, which equates to one in every five Americans. Of the 61.8 million Americans, approximately 41% report they speak English less than very well.¹³ Communication with caregivers and patients who do not speak English well can pose challenges of which clinicians should be aware. Clinicians rely on interpreters to obtain important information for effective treatment in these cases. Common challenges include misinterpretation of what the clinician said due to lack of specialized knowledge, misinterpretation of what the caregiver reports, or significant shortening or lengthening of the clinician's or caregiver's statement. In many states, interpreters are not required to have any formal medical training. Clinicians can combat some of these concerns by providing baseline education on key concepts that will be discussed prior to visiting the patient. Key terminology sheets in simple language also help clarify concepts for the interpreter. Clinicians should feel empowered to ask clarifying questions if they feel an interpreter is not accurately interpreting what was said.

Communication between caregivers and clinicians can be an issue regardless of

primary language. Caregivers balance numerous doctors, specialists, and therapists as a part of their child's care. This results in multiple appointments each week, which can become even more complicated for caregivers with additional children or work responsibilities. When completing a nutrition assessment, it helps to provide specific requests to the caregiver for follow-up. For example, the RDN should specify when anthropometrics should be reported to the RDN, the timing of follow-up visits, and the method for communicating recommendations to other caregivers or specialists. Being transparent with the family will help manage expectations for both parties. Ideally, follow-up reminders should be communicated via email, phone call, or text when additional data are needed.

HIPAA adds an additional layer of complexity when communicating with caregivers. Clinicians cannot leave voicemails that contain patient information unless the family has signed a release that allows it. Text messaging is a popular way of communicating with families; however, texting health-care information requires additional precautions. Secure applications are available that encrypt inbound and outbound text messages and should be utilized when possible. Families can also sign a release that indicates they prefer communication via text message, recognizing this is an unsecured method of communication unless secure applications are utilized. In addition, email can pose challenges depending on each facility's encryption software. It is common that medical facilities have a method to encrypt emails or will encrypt emails automatically upon sending to prevent hacking on the outbound path. Families may not have the same technology, putting sensitive health information at risk. Reading encrypted emails may also require creating a personal account within that facility's website. Encrypted emails may not be read or received for caregivers that are not tech savvy or do not wish to create an account.

Communication with providers can also be challenging due to the nature and demand

of the health-care system. Reaching the provider can be especially difficult if he or she does not belong to the organization where the RDN is employed, causing the RDN to communicate through the provider's nurse coordinator, fax, or email.

Communication between hospital EHRs and home care EHRs may pose additional challenges. If the home care is affiliated with the hospital system, information is readily available as they typically utilize the same EHR. If the home care is independent and does not have the same EHRs, information is much more difficult to obtain. Requests must go through the hospital medical record department, which requires a signed release of authorization by the caregiver and often a formal request sent via fax. Delays in any part of this process can negatively impact the patient.

Research Needs

Limited research is available for pediatric home care best practices. Children with complex medical diagnoses are living longer. Therefore, guidance is needed on how to best manage nutrition status as children age in the home care setting. Research is needed not only on home management of complex pediatric disorders, but also on the benefits of RDN visits to this population to help support third-party payment for RDN services.

Call to Action

Home care for the pediatric population is multifaceted and requires a multidisciplinary team. The hospital and home care teams should always strive to improve the practice and process of transitioning patients between facilities. Working together will ultimately improve patient outcomes and overall satisfaction.

CPEU Codes

5030 – Home care
 5070 – Pediatrics
 5400 – Case management
 5410 – Client protocols, clinical guidelines
 5440 – Enteral and parenteral nutrition support

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Dietitians in Nutrition Support Launches Advanced Practice Residency!

Dietitians in Nutrition Support (DNS) is pleased to once again offer the Advanced Practice Residency (APR) in Nutrition Support for Adults to qualifying proficient registered dietitians nutritionists (RDNs). All RDN “residents” can continue to work in their home facility while enrolled in this 12-month, online educational pathway that features a five day, supervised practice rotation at Cleveland Clinic that is individualized to address residents’ specific interests. The APR is not a dietetic internship but rather a residency designed to direct practicing dietitians with several years of nutrition support experience toward achieving an expert level of professional performance in nutrition support through the convenience of a primarily online learning format. Four applicants will be accepted to participate.

APR Program Goals:

To train proficient registered dietitian/nutritionists to become expert clinicians in the management of nutrition support for adults through the application of evidence-based practice.

Curriculum Structure:

- Distance, e-learning format
- Program-focused didactic courses (first six months) then monthly (second six months), all led by experts in the field of nutrition support
- Capstone project
- Mandatory five-day supervised practicum experience at Cleveland Clinic in Cleveland, OH within the first three months of the program
- Completion of all requirements results in a certificate that can be used to claim 75 CEUs through CDR
- Anticipated start date: March 17, 2019

Eligibility Criteria:

- Must have been an RDN for a minimum of four years

- At least three years of adult nutrition support experience within the past three years
- Master’s degree is preferred but not required
- Must identify a qualified mentor (i.e., advanced level practice RDN, RN/NP, Pharm D, MD) at the home facility who will agree to assist the resident with the capstone project and other work throughout the program
- Submission of a professional portfolio with the application
- At this time, international candidacy is not being considered

Program Fees:

Tuition and fees: \$3,000

- To secure a spot, a nonrefundable deposit of \$500 will be due at time of notification of program acceptance
 - Of the remaining program fees, \$1,250 will be due upon program initiation and \$1,250 due at the time of the supervised practicum (May 2019)
- Tuition does not include travel, lodging, or meals for the Cleveland Clinic portion of the program
- Check or credit card accepted from the resident or resident’s home facility

Questions?

Contact us at apr@dnsdpg.org.

Apply Today! To download the application, go to: <https://www.dnsdpg.org/page/advanced-practice-residency>.

Application is due by August 1, 2018.

Notification of acceptance will be given by September 1, 2018.

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