Purpose

The Nemours/JEA partnership proposes Remote Home Monitoring and Internet access to a patients electronic medical record (MyChart Functionality) via Broadband over Power Line as a means to address pediatric chronic disease, to test the use of new technologies, to retain and retrain health providers who are in high demand, and to create and attract new jobs within the City of Jacksonville. The project is expected to reduce complications of asthma, to increase access to under-served children, to enable interactivity in self-management, and to improve health literacy, quality of life, and self-efficacy. Nemours and JEA will initially focus on children with asthma in the Springfield neighborhood of Jacksonville, Florida.

Background and Significance: Approximately 20 million U.S. children (18%) have a chronic disease that requires health services beyond that required by children generally (Newacheck et al., 1998; Farmer, 2001; AHRQ 2002). According to Schiffman et al (2001), a few decades ago, 80% of children with serious chronic illnesses died abnormally early—today they are able to survive. Children with chronic diseases require complex ongoing care performed by multiple health care providers. As a result, coordination of their care and the logistics of gathering and storing information about their condition to support their care have become new challenges for providers.

All families with children who have chronic illness are under extraordinary strain while trying to comply with treatment regimens. However, disenfranchised families, who have the least support and resources, are at an even higher risk for chronic threatening illness. Demographically, families living below the federal poverty level (FPL) were 30% more likely than those above the FPL to have children with special health care needs. Children with chronic illness from one-parent households are more likely to have a less educated head of household and are 40% more likely to have an existing special health care need compared to two-parent families (Newacheck et al., 1998).

Problems: (1)**Access:** According to Mayer, Skinner & Slifkin (2004), children with special health care needs are vulnerable because of their social circumstances. Accordingly, poor and near-poor, children are significantly more likely to have unmet needs for routine and sub-specialty care compared with non-poor children (2) **Knowledge about illness:** Knowledge is necessary but not sufficient for successful self management skills. Health literacy is a combination of competencies, including the ability to complete basic reading and numerical tasks necessary to function in the health care environment (i.e. read and comprehend prescription bottles, appointment slips, and other essential health related materials needed to ensure successful outcomes). Research indicates populations with the highest prevalence of chronic, life threatening illness and the greatest need for health services had the least ability to read and comprehend information needed to function as a patient (Parker, et al, 1999). (3) **Self-Management Skills:** There is a need to design medical treatments to be sensitive to the dynamics of individuals and their families (Schultz, 1980). The traditional medical model involves one-way dissemination of information from an authoritative source (physician) to a passive user (patient). Adult learning theory clearly demonstrates that this model does not optimize education or motivation (D'Alessandro & Dosa, 2001). Patients with special health care needs (or in pediatrics, parents/family caregivers) are ultimately personally responsible for mastery of and fulfillment of day-to-day self-management. Patients and family caregivers are often best able to gauge the acuteness of their

symptoms and the efficacy of the prescribed treatment. As a result, they must be active participants in their treatment, and, indeed, must adopt self-management as a life-long task. (Celler, Lovell, & Basilakis, 2003). (4) **Complications of pediatric chronic illness:** Children with chronic illness also encounter both direct and indirect costs of illness. Directly, children with chronic illness account for less than one-fifth of the national child population; they account for greater than four-fifths of children's health care expenditures. Indirectly, compared to healthy children, children with special health care needs spent three times as many days sick in bed (or 52 million days sick in bed). Additionally, children with special health care needs had three times as many school absences (or 58 million school absence days) as their healthy peers (Newacheck et al., 1998). It is estimated that many pediatric hospitalizations could be avoided if more time were spent educating parents and children on (1) adequate medication adherence, (2) taking preventative measures, (3) a more through understanding of the child's medical condition (Flores et al, 2003)

Pediatric Asthma: Asthma is a prime example of a pediatric chronic, life-threatening illness that affects U.S. children, has been identified as a national health priority and requires strict treatment adherence. Asthma affects approximately 5 million children nationally making the disease the most common chronic pediatric disease. Asthma is one of six pediatric diseases that account for 90% of avoidable pediatric hospitalizations (Flores et al, 2003). Unfortunately, statistics do not take into consideration missed work time by patients' parents due to asthma (AHRQ). Asthma patients must monitor biologic indicators, select and correctly administer medications, and avoid triggers that exacerbate their asthma. Additionally, asthma patients are expected to appropriately use but not overuse emergency department care, primary care services, and sub-specialty care services. To meet these treatment regimen expectations, patients need information and competencies and must have sufficient reading, computational, and self-management skills to use the information/competencies (Parker, et al, 1999).

Proposed Solutions: Nemours and JEA propose Remote Home Monitoring (RHM) services and access to Internet based Electronic Medical Record functionality (MyChart-see Appendix H) interventions via Broadband over Power Lines (BPL) in the Springfield neighborhood of Jacksonville, Florida (See Appendix E for map). The 2000 Census statistics describe Springfield as one of the most impoverished within the City of Jacksonville. Thirty-two percent of the residents of this area have at least one disability, 40% of the residents have less than a high school education, and 62% of grandparents have primary responsibility for their grandchildren. African American and Hispanic/non-English speaking individuals are over-represented in this area. When compared with the entire city, more than 43% of households with children reside below the poverty standards, and 63% of adults are unemployed. Nemours Children's Clinic patients residing in this community are a profile of children likely needing interventions to address problems of access to health care, insufficient knowledge about their illness, disease management skills, and complications of illness for asthma patients.

Newly diagnosed children with asthma, and those who are experiencing difficulty with asthma management, who are treated by Nemours, will be invited to participate in the project. These participants will be loaned remote home monitoring equipment, and issued a refurbished computer or other suitable electronic device. At regularly scheduled times, or in times of distress, the patient/family member will connect the home

monitoring equipment via BPL, and with video streams, be able to talk with a Nemours clinician. RHM encounters will include transfer of biologic monitoring readings that will be interfaced with the Nemours Electronic Medical Record (EMR) creating a more complete record for the child. The healthcare professional will provide feedback, additional education, and supportive counseling as interventions to guide appropriate disease self-management. The computer will be used by the patient to visit My Chart, an interactive function of the Nemours electronic medical record, to record or review health information or to research health information. My Chart will reinforce the patients' understanding of their disease and their self-efficacy skills.

In order to increase patient self-management and decrease dependence on pediatric sub-specialty care, the proposed intervention will taper down to provide a mechanism to transition the child from regular RHM services to routine interactive involvement with the self-management of his/her disease. At the end of the "loaned" RHM duration, patients will still have an interactive dynamic with their health care. Through a telephone connection, patients will be asked to take peak flow readings and enter information into My Chart. The information will interface with the EMR and be reviewed with clinicians. Clinicians will provide the same level of support, but will encourage interaction via MyChart.

Anticipated Outcomes: Nemours and the Jacksonville Electric Authority hypothesize that remote home monitoring services transmitted via BPL, coupled with interactive EMR functionality, will benefit children with chronic, life-threatening illness by: (1) enabling more customized, interactive consultations with patients within their home environment, (2) interfacing biologic monitoring data with the EMR and providing clinicians/physicians with a more complete picture of the severity of the child's illness, (3) capturing data in the Nemours Data Warehouse to demonstrate replicability in other markets, (4) reducing complications of asthma, (5) increasing access to under-served children, (6) determining patient, family, and provider satisfaction with remote home monitoring and with interactive access to My Chart, (7) testing the functionality of BPL technology for delivering remote home monitoring services, (8) improving health knowledge and quality of life, (9) developing continuing education opportunities that address remote home monitoring and clinical informatics as a recruitment and retention tool for health professionals, (10) creating and attracting health and technology jobs to Jacksonville.

Innovation

(1) Use of Broadband over Power Line (BPL). Nemours and JEA will pilot Remote Home Monitoring via an emerging telecommunications technology, Broadband over Power Line. Currently, there are only 15-20 small pilot projects in the United States testing BPL technology mainly as commercial Internet Service Providers (ISP). Only two or three cities in the U.S. have made substantial citywide commercial investments in BPL infrastructure. Examples are Manassas, Virginia, and Cincinnati, Ohio. The target area of Springfield in Jacksonville is a test bed for new JEA technology with pilots for Wi-Fi and Street Light Monitoring currently underway in addition to the commercial deployment of JEA's Network Meter Reading system. (2) **Use of BPL in healthcare-RHM.** We have been unable to identify another electric utility company and a health system partnership using BPL to enable patient access through remote home monitoring equipment. This innovative concept allows clinicians and patients to connect over

broadband with unprecedented bandwidth availability. Most telemedicine vendors only create equipment compatible for telephone modems, a few vendors enable equipment for broadband, and no identified vendors have BPL compatible equipment. (A Premise Connection will be used to make an Ethernet port compatible with an electrical outlet-see Appendix I.) BPL technology provides a speed and consistency that surpasses that of telephone lines and is almost universally available, surpassing the limited access to rural and disenfranchised areas that hinders traditional broadband. With BPL, there is already an infrastructure through the power lines that will potentially enable affordable access to broadband for rural and under-served citizens. **(3) Telemedicine link to EMR.** Few healthcare institutions have a completely installed electronic medical record, and even fewer organizations that treat children have an operational electronic medical record. Nemours is the only pediatric provider in the U.S. with a pediatric electronic record operating on a single electronic platform. The link of RHM and the EMR increases physician productivity and reduces the chance for error in manual re-entering of data. **(4) My Chart functionality.** Only a handful of health care organizations in the country are using My Chart. No organizations are utilizing My Chart to enhance the transition of children with chronic disease from RHM services into self-management with a focus on increasing the health literacy of the patient and family. **(5) Model for a "wired" city.** A BPL infrastructure is an innovative way to create and attract jobs to Jacksonville. The degree to which an area is "wired" has been positively correlated to the number of high paying jobs in the area.

Community Involvement

This unique partnership of a public utility company and a healthcare provider is the result of a longstanding commitment by both organizations to be active listeners for community needs and active innovators for proposing solutions. The diverse group of stakeholders providing letters of support represent the public and private sectors, profit and nonprofit groups, trade associations, insurance payors, and governmental and legislative bodies. The group's variety provides further evidence of the community support that this partnership and proposal command, as well as the ability of our supporters to help maximize the project's success.

Great attention was paid to the uniqueness of the target area selected for the project's implementation (See Appendix E). Nemours has a lengthy history of serving these children and families, and JEA provides water, sewer, and electricity service for these families. The partners selected this location and target population with full knowledge of the challenge, because this was the area where the greatest good could result. Nemours will cultivate an indigenous citizen's council to assist with the planning, implementation, operation and evaluation of this project. Representatives from the Mayor's Springfield Neighborhood Association, major churches, schools, as well as parents and children will form the Citizen Council, help promote the project within the neighborhood, and serve as "ambassadors" for future project replication. Given the low literacy and educational levels of this community, the project has been designed to allow the participants to keep the computer, monitor and software used during the project. The training provided through the use of My Chart and continual access to the home computer will establish a base from which to continue to build health care knowledge.

Because this technology is new, there are no established "demand" statistics for the Jacksonville community. However, Nemours experience with a small RHM pilot in

Pensacola has confirmed the value of remote home monitoring. The Pensacola project has only been in existence for 18 months, and the waiting list for program access is more than 4 times longer than the number of available slots. The healthcare professionals, parents and patients have reported great satisfaction with remote home monitoring, and the clinical outcomes have been impressive. Input from the Pensacola stakeholders has helped to shape the design of this grant application. Another stakeholder, the Blue Foundation for a Healthy Florida, funded the original pilot in Pensacola, has recently expanded that funding, and has provided input into the design of this application in order to begin studying the feasibility of reimbursement for remote home monitoring services.

The strongest evidence of the project's sustainability after the expiration of grant funding is the dramatic investment of financial and intellectual capital that both partners have already made. JEA and Nemours will both continue to devote organizational energies and staff time to plan for this project over the next five months so the federal monies and the 24-month timeline can be maximized if the grant award is made.

Evaluation

Evaluation Strategy. This project will include formative, process (output) and outcome evaluation approaches. Mixed methods that will include the collection of qualitative and quantitative data will be utilized. Focus groups, observation, in-depth interviews and paper record documentation will be used for the formative and process evaluation. The outcome evaluation will employ a quasi-experimental design whereby patients receiving RHM will be compared to a control group. The control group will be Nemours patients selected from catchment areas where BPL access is not available. **1. Formative Evaluation.** Focus will be on designing a program that closely meets the needs of the target population. Children and caregivers will be asked to provide feedback on the draft of the proposed intervention. A pilot will be conducted to test the delivery of the intervention and RHM system. At the conclusion of the pilot, children and families will be asked to provide feedback on the usefulness of the system, practicality, perceived effectiveness and weaknesses. These comments will be analyzed qualitatively. The final intervention will be revised accordingly. **2. Process Evaluation.** Process evaluation will focus on documentation of output delivered, technological requirements, and lessons learned to deliver this service. The evaluation will also address the delivery of the service and satisfaction with use. The questions to be addressed are: (1) What are the required technology protocols for implementation of broadband over the telephone? (2) Was the remote monitoring system installed? What are the costs of installation? How long did it take? (3) Can patients interact with providers via video link? Can patients interact with My Chart? (4) Can data from spirometry measurements be accurately transmitted and recorded to the electronic medical record? (5) Are health providers satisfied with the use of RHM to deliver services? (6) Are patients satisfied the use of RHM to receive services? Is there a subset of patients who benefits more from the RHM service? 3. **Outcome Evaluation.** The goal of the outcome evaluation will be to assess the effectiveness of RHM on access to care and outcomes. Evaluation questions will focus on patient outcomes to determine if differences result as a consequence of Remote Home Monitoring. The questions to be addressed are: (1) Does RHM improve access to health care services? (2) Does RHM lead to an increase in patient/parent asthma knowledge? (3) Does RHM lead to an improvement in self-management skills for

children and parent/caregiver? (4) Does RHM lead to an improvement in patient and parent/caregiver outcomes? (Quality of life, disease severity, service utilization.)

Data Collection and Analysis Plan. (1) Data collection for formative evaluation. Formative evaluation will be conducted within the first 6 months of the project. Focus group protocols, structured in-depth interview surveys, and activity logs will be used. (2) **Data collection for process evaluation**. The RHM program will be evaluated on a quarterly basis during Year 1 and every 6 months during Years 2 and 3. Patient satisfaction will be assessed using the ServQual, an instrument currently used at Nemours, and by means of the CSQ-8 (Client Satisfaction Questionnaire short form). A validated provider satisfaction survey will be identified. (3) **Data collection for outcome evaluation**. Data will be collected from the patient and parent/caregiver at baseline, immediately post-intervention and after a four-month follow-up to assess short-term outcomes. To minimize recall bias, data on service utilization will be collected monthly. Measures to be used are a previously validated survey to collect patient demographics, access to care, service utilization, and the PedsQL Asthma version. A questionnaire will be designed to assess asthma knowledge. Asthma self-efficacy will be assessed with a Likert-scale questionnaire. (4) **Data analysis:** Qualitative data collected from focus groups and in-depth interviews will be transcribed and coded. Data collected as part of the outcome evaluation will be analyzed using the appropriate statistical analysis methodologies. The analysis will include frequency distributions on all variables. For categorical variables such as gender and ethnicity, frequency analysis will be conducted. For continuous variables, measures of central tendency and dispersion will be presented. The primary goal of this analysis is to compare access and outcomes between groups. The following are expected to be confounding variables: disease severity, race, sex, parental/caregiver education, age of child, socioeconomic status, age at diagnosis, whether the parent/caregiver also has asthma, prior access to internet. Accordingly, models will adjust for case-mix, namely, differences in patient, provider, and practice characteristics. The model will test if the RHM leads to improved access, quality of life, better outcomes, and increased patient satisfaction.

Evaluator and Qualifications. The Nemours Clinical Management Program (NCMP), a distinct division of Nemours that facilitates health services research and quality improvement activities, will serve as the evaluation team. NCMP, directed by Ian Nathanson, MD, a senior level physician experienced in health services and outcomes research, includes staff with training and experience in research design, program evaluation, evidence based medicine, information technology, statistics and business development. Dr. Nathanson will be responsible for the overall conduct of the evaluation. The evaluation team will include Gabriela Ramirez-Garnica, Ph.D., MPH, Associate Director of NCMP, who holds a degree in epidemiology. All evaluation activities will comply with HIPAA and Institutional Review Board requirements.

Project Feasibility

Nemours is the largest national pediatric sub-specialty organization on a single electronic platform with an installed EMR (Appendix D). Nemours has previously tested a stand-alone RHM pilot program in Pensacola, Florida. The RHM technology, while useful, does not integrate with the EMR. This absence means that the "force functions" and "rules" guiding prescription dispensing patterns, etc., are not being utilized during remote monitoring encounters. The data received from the patients must be manually

reentered into the EMR, creating the possibility of transcription error, and a delay in access to newly created intelligence about the patient's condition because there is no real time interface. Additionally, opportunity exists for patients to be active participants with their electronic medical record through a program called My Chart. However, the technology is new and deployed at only a few health care institutions. Nemours has the ability to create an electronic environment to bridge the continuum of care for pediatric patients. To build the pilot for a "next generation" health system via BPL, Nemours programmers will build various interfaces to enable data flow from the biologic monitoring peripherals, video streams from the "virtual" encounters, and data from My Chart to a common EMR.

Nemours recognized the need to seek out an additional telecommunications vehicle to enable RHM encounters after the pilot program revealed patients' phone lines are frequently disconnected due to a lack of bill payment. Nemours considered alternative telecommunications technologies, but felt BPL offered the most benefits due to synchronous communications. Additionally, BPL offers an in-place infrastructure from power lines and the potential for replication in rural areas (where future children may receive RHM Services to enhance subspecialty care). Nemours motivation to improve access to care for children with asthma resonated with JEA's goal to initiate a new research project into the latest generation of BPL technology and best practices.

JEA has been researching the Broadband over Power Line (BPL) technology for more than two years. Information was collected on BPL vendors, BPL technical associations, and potential municipal and investor utility BPL users. Recent improvements in technology applied to BPL and other utility pilot projects are showing the advantages of BPL. JEA selected BPL to connect pediatric patients to Nemours for four reasons: (1) larger bandwidth (speed > 1 Mbps) of the latest generation of BPL, (2) BPL's same fast speed for download and uploading data, (3) the "ubiquitous footprint" of the JEA electric grid into every home and business in Jacksonville over existing JEA/customer electrical wiring conductors, (4) the reported lower overall costs of BPL compared to other hardwired broadband technologies.

Nemours and JEA will connect the RHM equipment via BPL through a commercially available device called HomePlug (Appendix I). BPL equipment will be coupled onto the JEA medium voltage electric grid to carry the high frequency data communications signals from electrical substations or other facilities with fiber optic cable and electronics to, through, or around the transformers feeding electric power to JEA customers (see Appendix I). Power line modems will be plugged into the home's existing electrical outlets to provide both electric power and high frequency Ethernet or DSB signals to intelligent PCs, monitoring equipment, video terminals, etc.

Both Nemours and JEA are seeking opportunities to improve existing infrastructure (EMR, Power Lines, respectively) to improve services to end users. Nemours has consulted with participants in the Pensacola pilot program and looked at pilot results. This information has helped the organizations to more effectively construct the Jacksonville RHM/BPL proposal from a patient's perspective. JEA has also listened to customer input (as evidenced by the organization enthusiasm to partner with Nemours) to provide a communications infrastructure for RHM to link My Chart to the Nemours Children's Clinic at Jacksonville.

Nemours and JEA are confident this project will be completed within the scheduled timeframe. A number of JEA departments are performing due diligence reviews of JEA stakeholder requirements, engineering, communications, network, electric grid, safety, financial, regulatory, reliability, etc., for the BPL Pilot. It is planned to contract with an experienced BPL consultant who will assist JEA with all functions through the research, design, construction, installation, testing, and operational phases.

In order to enhance project feasibility, Nemours has built time into the project plan to facilitate the taper down effect. The project plan calls for Nemours to purchase and install hardware and software, recruit project staff, recruit patients (see Project Plan, Appendix). Patients will receive a 2 phase intervention. Phase 1 will last 4 months and will include RHM virtual encounters, spirometry, peak flow monitoring, and access to My Chart via BPL. During Phase 2, which will last 4 months, patients will be asked to continue peak flow monitoring and will have access to My Chart. Additionally, patient groups will receive a four-month follow up- and subsequent follow-ups (to be determined) to conduct an evaluation of long-term outcomes. The project plan includes a one-month lag time to enable equipment changes, set-up, and train patients entering the RHM pilot program. Additionally, formative, process, and outcome evaluations, and a six-month pilot have been appropriately budgeted for in terms of cost, time, and scope.

The Nemours Principal Investigator, Francis Koster, Ed.D., Vice President of Corporate Services, will provide administrative leadership and knowledge of the overall informatics and information systems investments at Nemours. Dr. Koster has also worked in the energy industry. The JEA Principal Investigator for the RHM/BPL Pilot, John R. Beatty, is deeply involved in this and all other JEA communications studies and pilots mentioned in this document.

JEA and Nemours are committed to meeting all relevant privacy and security requirements. It is expected that the use of BPL technology will provide faster and more desirable results at a lower overall cost than existing telephone modem, DSL telephone, or cable modem systems. These communications technologies will be compared.

A maximum of thirty-five (35) Nemours patient homes and approximately ten (10) JEA facilities are expected to be connected at any one time during this pilot. Numbers of pilot locations that can be served are limited by pilot / grant funding and management direction. The pilot will determine the feasibility and possible recommendation for expanding BPL throughout the 350,000-customer JEA electric system. Next steps for future expansion and operation of the JEA BPL network and the Nemours Remote Health Monitoring program will be based on the positive and/or negative results of the JEA BPL Pilot/Nemours RHM project. New applications like electric outage reporting, JEA voice over IP communications, customer electrical service control, etc., will be considered for testing. Appendices F-G reference intervention and project timelines.

Project status reports and all "lessons learned" will be prepared and disseminated to internal JEA stakeholders and to others who have an interest in this project's success. Technical and management personnel will do internal JEA and Nemours progress reviews. Testing results for the JEA/Nemours BPL Pilot project will be documented in a Final Report. Opportunities to present, to discuss, and to share all elements of this project with other utility professionals, national communications associations, local civic groups, and medical professionals are expected.