Letter from the Medical Director
Perri Klass, MD, ROR Medical Director

As the year comes to an end we approach the traditional time for Reach Out and Read programs across the country to be asking supporters for contributions. This year poses a particular challenge to all of us in the non-profit world. So I hope that you will excuse me if I write now with some passion about the importance of what we all do, even in this new and frightening world.

At a time of fear and uncertainty, and this is certainly that, the homebound pleasures of spending time together, of reading aloud, of close contact between parents and a young child, become even more important. As many Americans feel new kinds of fear and worry, they hug their children closer. As even young children struggle with disturbing images on television or the sense of adult worry and anxiety, the reassuring sound of a parent's voice reading aloud, the comforting colored world of a children's book, becomes more and more important to the child – and to the parent. Think about what you are doing to help your own children through this time – and help us help more parents to understand the value of stories and bedtime rituals and comfort.

As economic times worsen, our target population, the children growing up below or near the federal poverty level, gets larger and poorer. Parents who might once have had a little discretionary income now may not. The books that are given out by pediatric clinics to these families are more and more likely to be the only books they have.

And so, for all these reasons we need to continue to ask for help and support – so that Reach Out and Read can continue its important work, so that more children can know the comfort of a parent's voice reading a story – at bedtime – at a troubled time – and every day. So that even in hard economic times, a child's home holds at least a small library of beautiful books, and a parent who knows how to help the child enjoy them. And yes, so that we can help more of the children who are at risk, but who collectively constitute the future of our country, grow up with the joys and possibilities of books and reading.

A Report from the ROR National Conference – Health Literacy

Terry Davis, PhD, Professor of Medicine and Pediatrics, Louisiana State University
Ruth Parker, MD, Associate Professor of Medicine, Emory University School of Medicine

Health Literacy has been defined as the ability to read, understand and act on health information. At the June conference, Drs. Davis and Parker presented an overview of this critical issue and how it is linked to the efforts of ROR.

How often do we as practitioners think about what it is like to be a patient today? Do we only think about it when we are patients? To fully understand what is meant by the term health literacy, we must put ourselves in the patient role.

Twenty-five years ago, a newly diagnosed patient with asthma was prescribed theophylline and instructed on taking the medication diligently, and asked to return for regular visits to the physician. Today, such a patient is instructed on the use of multiple metered dose inhalers that probably have varying dosing instructions, sometimes given tapering doses of oral steroids for exacerbations, told to avoid environmental triggers, and asked to regularly record airway function with a peak flow meter. They are expected to comply with multiple medications, follow detailed instructions for self-management of a chronic condition, know how to access and use, but not overuse the services of a primary care provider, sub-specialist, and emergency room.

The practice of medicine and the delivery of health services in America have changed dramatically in the last decade. High costs and a desire to control them, advances in effective treatments and pharmaceuticals, and an increasing prevalence of chronic diseases and disability contributed to changes in both the practice and delivery of health services. Patients are increasingly expected to be “empowered,” able to quickly understand complex information, make complicated medical decisions and follow through with detailed self-care treatment plans. Unfortunately, the system we have created is based on a false assumption that all patients can be “empowered” partners in their own health care. Our system ignores the fact that almost half of the American population has limited literacy skills, which means they probably struggle to understand and act on basic health information.

Health literacy is increasingly important in the rapidly evolving world of medicine and health care. Functional health literacy is defined by one's ability to apply reading and numeracy skills in a health care setting. According to the results of the 1992 National Adult Literacy Survey (NALS), approximately 90 million American adults have low levels of functional literacy. These individuals are unable to locate, comprehend, or act upon information presented in simple text. These same Americans are patients in a complex health care system, and many struggle with routine health care tasks.

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Federal Appropriations Update
Matthew Veno, Director of Government and External Affairs

While the nation adjusts to a world drastically altered by the September 11th tragedies and their aftermath, members of the U.S. Congress struggle to continue with the business of government during what can be a contentious and sometimes chaotic end of session. This business includes passing the 13 spending bills that must be completed every year, one of which is relevant to ROR’s federal funding.

With this backdrop, the profile and recognition of Reach Out and Read has been raised significantly among policy makers on Capitol Hill this year, thanks to the energy and enthusiasm of ROR sites nationwide. We have made big gains this year, and the bottom line is that more legislators in key positions in the Congress know about ROR and are helping to advocate for us.

A recent, tangible manifestation of this progress was to enlist members of the Senate as signers on a letter, urging their continued support of ROR, to Senators Harkin (D-IA) and Specter (R-PA), chair and ranking member, respectively, of the appropriations subcommittee that handles health and education. The letter, the first of its kind about ROR, was circulated in the Senate during the months of August and September, and delivered to “the appropriators” on September 17.

Nineteen members of the Senate signed the letter, including five Republicans and fourteen Democrats. The list included some very prominent members of the Senate, including eight committee chairmen, and two ranking minority members. Signers also included three freshman members of the Senate, and six of the twelve women Senators.

What made this effort so successful was the number of sites that called their legislators’ offices, urging their Senators to sign on. To all those ROR sites that participated – thank you!

Specifically, our effort this year is focused on increasing ROR’s funding in the Labor, HHS/Education appropriations bill. With this funding, we can continue to support ROR programs nationwide. With 100 new applications received last quarter, the level of interest in this program continues to grow. This public funding, in addition to the more than $7 million in private funding secured by the ROR National Center and local programs, allows us to keep pace with this demand.

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New Tools for Training and Re-Training
National Center Announces ROR On-Line CME Course
Ron Bailey, Director of National Programs

One of the most important tasks in keeping ROR programs strong is making sure that participating medical providers deliver anticipatory guidance and give the book to the child and parent in the exam room. These are the two most important components of the ROR model. Given staff turnover and with incredibly busy on-site “physician champions” who are responsible for ongoing training, it is possible that some physicians stray from these two requirements. The National Center considers some annual in-house “refresher” training of providers a key element in keeping a ROR program healthy. Several new tools for re-training providers are soon to be available:

On November 19th, 2001, the ROR National Center will release a one-hour on-line AMA-approved CME provider training course for pediatricians. The course content is approved for one CME credit for pediatricians. Watch the ROR website for the address!

Partnering with Boston University School of Medicine CME office, we are also working to have this course content approved for family practitioners, pediatric nurses and nurse practitioners. The course instructor is Perri Klass, MD.

Supported through a generous grant from the Pritzker Cousins Foundation, the CME course will be available to physicians without cost for the next year. We hope that having a very user-friendly updated on-line CME option for reviewing the standard ROR training material will lead to its being widely used for re-training, especially for providers who were first exposed to ROR several years ago.

While the on-line ROR course can never replace the interactive face-to-face workshops our Regional Trainers offer, it provides an important training option. We also anticipate that it will be useful for providers who are unable to attend a Grand Rounds and workshop presentation in their region. One feature of the CME course is a summary review of the recent pediatric literacy research. The small quiz at the end of each section will give us some information about which parts of the training are most difficult to remember.

(A similar on-line “workshop” for ROR Program Site Coordinators and volunteers is scheduled for mid-2002 release by the National Center staff.)

The National Center also has a new (July 2001) ROR PowerPoint presentation designed for medical providers who are training other physicians and nurses in the ROR model. There are 45 PowerPoint slides or overheads on the file, and a set of brief speaker notes in Microsoft Word, which are now available to physicians and nurses (as an email attachment, or snail-mail on a disc) to be used in an LCD training format. As funding is available we will produce a few hard-copy slide sets for distribution.

This recently developed ROR PowerPoint presentation places more emphasis on the unique role of the physician and on children’s early language development, and moves succinctly through accessible summaries of three ROR-related research articles. We view these slides or overheads as wonderful vehicles for re-training physicians and nurses, especially at informal noontime clinic workshops, as well as introducing new colleagues to the strategies of practicing pediatrics with ROR.

Providers responsible for on-site ROR training in existing programs can call Programs staff at the National Center, Jackie Miller or Jennifer McNamara (617-629-8042) to get this PowerPoint file.

We urge all Medical Directors of ROR programs to access these two important training tools, and to consider an on-site refresher workshop or designate a special ROR CME week by providing the course address to physicians in your clinic.
At press time, language in support of ROR was included in the appropriations bill that passed the House of Representatives, and that which passed by the Senate appropriations committee. Stay tuned to our website (www.reachoutandread.org/grassroots.html) for updated information.

Federal Appropriations Update

(continued from page 2)

Through a partnership with Pfizer Consumer Health Care and CVS/pharmacy, Reach Out and Read programs will receive 100,000 new books this year. More than 2,000 CVS/pharmacy stores around the country will feature ROR on an aisle display. A portion of the proceeds from each featured Pfizer product purchased will go towards the purchase of books for ROR sites. We are very excited by this promotion and the books it will provide for our sites, as well as the increased name recognition it will yield for Reach Out and Read. We are grateful to both CVS/pharmacy and Pfizer for their continued commitment to literacy.

National Board Update

Reach Out and Read is pleased to welcome Lisa Marks Schwarz to the ROR National Board.

Lisa is a fundraising consultant specializing in corporate and foundation giving. Previously, she worked in fundraising at the Dana Farber Cancer Institute and Boston University. A co-founder of the Friends of Reach Out and Read, she has been an active volunteer with ROR since 1997. Lisa lives in Sherborn, MA with her husband and daughter.

Write In Reach Out and Read on Your United Way Pledge!

We have recently learned that Reach Out and Read programs can receive designated donations through local United Way campaigns. The process is easy—simply write in Reach Out and Read in the “Restricted Contribution” category on your pledge form. Many of our ROR friends and supporters contribute regularly to the United Way and we ask this year that you consider earmarking that contribution for Reach Out and Read.

Reach Out and Read sites or coalitions that have questions about this process should contact Anne-Marie Fitzgerald, Director of Development at the National Center, at 617-629-8042, ext. 226.

The new Developmental Milestones Poster translated into Chinese is presented at the South Cove Health Center in Boston.
The Impact of Parent Literacy Level on Parent-Child Joint Reading in an Inner City Clinic Population

Susan Berry, MD, Associate Professor of Pediatrics, Louisiana State University

In this study a cross-sectional design was used to survey 163 parents of 6- to 11-month-old infants coming to the New Orleans Health Department Child Health Clinics prior to the beginning of their ROR program. Parents were surveyed concerning their own literacy habits and their joint reading activities with their children. The literacy nature of the questions was masked with questions about other activities to avoid bias in answers. Parents were then asked to complete the Rapid Estimate of Adult Literacy in Medicine (REALM). This test takes about five minutes to administer but correlates well with the WRAT, the PIAT, and the Slossen tests of reading achievement.

In this inner city African American population, literacy level was frequently lower than educational level would suggest. Although all parents in this survey had entered high school, 43% had an eighth grade reading level or less, and of those who had completed high school, 32% read at an eighth grade level or less. Child Centered Literacy Orientation (CCLO) as defined by Pamela High in 1998 was used as a measure of joint reading activities. In this population 47% of parents had a positive CCLO. Parents with a sixth grade reading level or less were unlikely to model reading for pleasure and were twice as likely to lack a CCLO. Using a logistic regression analysis, controlling for marital status, employment status, parent's age, child gender, daycare attendance, and income, those parents most at risk for lack of a CCLO (and therefore low frequency of joint reading), were those having less than ten total books in the home and those parents not completing high school (OR 7.0, p=.001 and 2.8, p=.033, respectively.) When both of these risk factors were present, parents were 18 times more likely to lack a CCLO. Having less than a sixth grade reading level ceased to be a significant predictor when educational level was added to the equation, indicating that educational level is a better predictor than reading level of joint reading activities. Marital status and income were not significant predictors of risk in this population.

In conclusion, families with less than ten total books in the home and those with a caregiver who did not complete high school are at higher risk for lack of joint reading activities in this already high risk population. These are easy risk factors to assess and could help in targeting more intensive interventions to those families most at risk. These families may benefit from a more intensive intervention, such as referral to adult literacy or family reading programs. While these risk factors may help in identifying children at highest risk, they should not be misinterpreted as identifying all children at risk.

In our previous work, children attending an intervention clinic with a longstanding Reach Out and Read program were compared to children attending a control clinic where ROR had not yet been implemented. The clinics were very similar sociodemographically; the only substantial difference between the clinics was the presence of ROR. In that study, we found that children attending the clinic with ROR received increased parental literacy support and had better language development (Pediatrics, 2001; 107: 130-134).

In our present work, we evaluated the effects of Reach Out and Read on children attending the original control clinic, two years after ROR was implemented there. The study design was a comparison of children presenting to an inner-city pediatric clinic before and after initiation of ROR in the clinic. The intervention group was a convenience sample of Latino and African American children 2-6 years old presenting for well-child care two years after the initiation of ROR. The control group was a similar convenience sample of children presenting for well-child care prior to initiation of ROR, each of whom in addition matched an intervention subject for age, sex and ethnicity.

Parental literacy support was measured with the READ subscale of StimQ. Child language was assessed using the One Word Picture Vocabulary Test or OWPVT for both receptive and expressive language (standardized for use both in English and in Spanish).

Analyses were performed for 65 pairs of matched intervention and control families, for a total sample size of 130. Intervention and control families were nearly identical sociodemographically. The main results (all statistically significant) were:

Parental literacy support: Intervention families had a mean StimQ-READ score of 13.9, compared to 11.8 for control families. Intervention families read an average of 4.7 days per week, compared to 3.9 for control families.

Language outcomes: On the receptive vocabulary test, intervention children scored an average of 99.1, compared to 84.4 for the control children. On the expressive vocabulary test, intervention children scored an average of 90.2, compared to 81.8 for the control children. In multiple regression analyses adjusting for child’s age, birthweight, gender, ethnicity and country of origin, and parent’s age,
education, language spoken at home, and history of homelessness, adjusted receptive vocabulary scores were 13.9 points higher in the intervention group. Adjusted expressive vocabulary scores were 7.6 points higher in the intervention group.

As with our previous study, we showed large, clinically significant effects of ROR on parent-child reading activities, as well as on children’s expressive and receptive vocabulary. Our results add to a growing body of evidence demonstrating the efficacy of Reach Out and Read.

Before and After Books and Reading (BABAR) Study
Robert Needlman, MD, Rainbow Babies and Children’s Hospital

This study was begun in May, 1998, as an offshoot of the Ambulatory Pediatrics Association Special Interest Group for Literacy Promotion in Primary Care – a group which meets annually as part of the larger Pediatric Academic Society meeting, and which includes many ROR leaders.

BABAR was designed to provide a measure of ROR program efficacy, that could be used by individual programs with minimal outside funding, and that would provide data that were comparable across sites. The study revolves around a one-page, ten-question parent survey. In addition to basic descriptive information, the key questions include three open-ended questions – do parents mention books or reading as one of the child’s favorite activities, as something that prepares children for school, or as a part of the child’s bedtime routine – as well as three closed-ended questions – does the parent ever read to the child, how many days per week, and how many books does the child have. The survey can be given in the waiting room, or in the doctor’s office, and takes only about 5 minutes.

The study design called for programs to administer 50-100 surveys to parents before the initiation of the ROR program, and then again approximately one year after (hence the “before and after” in the study’s name). The main goal of the study is to see to what extent introduction of ROR is associated with higher (we hope) rates of parent-reported literacy-promoting beliefs and activities. Previous published and non-published research suggests that this association should be strong. However, all of these studies could be considered efficacy studies – studies of the program under optimal, research-related conditions. The BABAR study, by contrast, could be considered an effectiveness study because it looks at how the program operates under real world conditions, in multiple different sites.

So far, we have data from 43 sites in 16 states, a total of 2008 children from 6 months through 5 years, with mean age of 24 months, from a range of cultural, educational, and linguistic backgrounds. Although diverse, the sample was not nationally representative. At baseline (“before”), 43% of parents mentioned books as a favorite activity, 33% included books at bedtime, and 51% included books as promoting school success (somewhat higher numbers than in most of the published studies). Most parents (84%) reported reading “ever,” with the average days per week being 4.3. The largest percentage of parents (34%) reported owning between two to ten children’s books, while only 11% had none or one.

Both before and after data were reported from a subset of ten sites, representing some 1006 children. Significantly more parents in the “after” group volunteered reading aloud as an activity that will help their children succeed in school (66% versus 57%, p<.005) and more “afters” reported ever reading to their child (93% versus 88%, p<.02). We did not find significant differences for the other outcomes.

Looking individually at the 10 sites that had before and after data, at least one significant difference, with “afters” exceeding “befores,” was found in eight of the ten sites, and were there many non-significant trends in the same direction. Generally speaking, the differences were clinically meaningful (for example, 26% reading at bedtime in one set of “befores,” versus 55% in the “afters.”) However, these results pale in comparison to the results of previously published trials, which generally have found large, significant differences in all or most of the parent self-report measures.

There are many methodological limitations to the study. However, it represents the first large-scale effectiveness study for ROR, looking at the program in real-life (as opposed to research-driven) settings. We need to devise meaningful, reliable, and feasible ways to monitor the ongoing effectiveness of our efforts. BABAR represents a step in that direction, but we still have a long way to go.

A Report from the ROR National Conference – Health Literacy (continued from page 1)

Clinical research studies have alerted practitioners to the magnitude of problems with health literacy. Among public hospital patients, 42% were unable to comprehend instructions for taking medication on an empty stomach, 26% were unable to understand an appointment slip, and 60% could not understand an informed consent document. The hospitalization rate was 50% higher for those with inadequate literacy, and one researcher estimated the excess costs associated with low health literacy to be over $70 billion annually.

In 1999, the Council on Scientific Affairs of the American Medical Association convened an expert panel to report on health literacy. The report used evidence-based methodology to review published peer reviewed literature and describe the consequences of inadequate health literacy, implications for practicing physicians, tips for communicating with patients, research issues, and policy implications. (Ref: JAMA.)

Reference:

Resource:
Health Literacy Introductory Kit, including video and teaching kit, is available from the AMA for $25 – contact Joanne Schwartzberg at 312-464-5355.
Success By the Numbers!

As of October 2, 2001 the most recent round of Progress and Sustainability reports indicate:

- A total of 1,349 sites - including 1,144 programs in 50 states, D.C., Puerto Rico and Guam; along with 205 additional “satellite sites” affiliated with larger clinics or hospitals.
- A total of 13,000 primary care providers have been trained at these sites on using the ROR model.
- Over 1,468,000 children are being served by ROR this year.
- Over $650,000 in sustainability awards made by the National Center based on eligible sustainability reports.

The progress report process, led by Jackie Miller, provided detailed information about programs, parents and volunteers. The work accomplished to make these elements work so successfully in so many programs is a tribute to the efforts of ROR Programs Coordinators across the country.

Please check the Reach Out and Read website at www.reachoutandread.org for future training opportunities.