

The American Immunization Registry Association
(AIRA)
Financial Statement
July 1, 2002 to June 30, 2003

Revenues

Membership Fees	\$8,395
Workshop Fees	5,620
Grants	286,901
Total Revenue	\$300,916

Expenditures

Personnel Services	\$133,113
Consultant/Subcontractor Fees	90,332
Legal Fees	0
Communications/Marketing	0
Printing	6,174
Travel	17,997
Meetings	6,279
Indirect Costs	32,015
Total Expenditures	\$285,910

Surplus/(Deficit) \$15,006

NOTES TO FINANCIAL STATEMENT

REVENUES

- Membership Fees:** Reflects all 2002 membership fees collected in all categories of membership: individual, organization and affiliate memberships.
- Workshop Fees:** Reflects fees collected for workshops held in 2002.
- Grants:** this category reflects grants received from the Centers for Disease Control and Prevention (CDC), All Kids Count (AKC) and Wyeth Vaccines.

EXPENDITURES

- Personnel Services:** reflects expenses to cover salary and benefits for two (2) full time staff: the Executive Director and the Resource Developer.
- Consultant/Subcontractor:** Fees: reflects expenses to cover consultant fees including the Executive Director (July 1-September 29, 2002), the Research Consultant, a writer/ editor, a graphic designer and the web site administrator/ designer. Also covers the Every Child By Two (ECBT) subcontract expenses.
- Printing:** covers costs incurred for printing various resource toolkits and guides as well as costs for reproduction of materials for meetings and workshops.
- Travel:** covers costs incurred for travel to conferences and project-related meetings by the two (2) AIRA staff and Research Consultant, AIRA President, Vice-President and Board of Director members and workshop leaders as approved by the funding source.
- Meetings:** covers costs for grant approved meetings and workshops.
- Indirect Costs:** MHRA overhead costs.

A Letter From the President

Dear Colleagues,

We can all be very proud of AIRA's accomplishments this past year.

Working collaboratively with our partners and peers in the immunization registry community, we are sharing information, knowledge, resources, and lessons learned as we strive toward meeting the Healthy People 2010 Goal: 95% of children < 6 years enrolled in a fully operational immunization registry. Building population-based immunization registries in every state and local community is a core component of our national strategy to protect all people against vaccine-preventable disease.

By pulling together as a community through AIRA, we are making the most of the resources we have. Using our resources wisely will be essential to reaching our common goals, especially in these times of budget crises and shifting priorities.

As you read through this report, I am certain that you will be impressed with the breadth and depth of AIRA's work. Our committees—Education, Technical, Bioterrorism, Provider Participation, Urban/City Registries – are tackling the most daunting challenges facing our community, and are working closely with the Centers for Disease Control and Prevention (CDC) to implement the national Immunization Registry Strategic Plan.

The Programmatic Registry Operations Workgroup (PROW), a collaboration of AIRA, CDC, and the Association of Immunization Managers (AIM), produced "standards of excellence" for use of immunization registries by immunization programs to increase the effectiveness of immunization program core functions. These standards were distributed to every immunization program and registry manager across the country. The National Vaccine Advisory Committee (NVAC) passed a resolution earlier this year endorsing the work of PROW. Currently, 12 demonstration sites across the country are pioneering the implementation of the PROW standards.

It has been deeply rewarding to serve as AIRA president these last three years. Bill Brand will be assuming the AIRA presidency in October 2003, and I will become past president. I am certain that AIRA will continue to flourish under Bill's leadership. To all AIRA members and supporters, I thank you for the privilege of serving as AIRA president and I look forward to working with you in my new role in the years ahead.

Sincerely,

Amy Metroka

The American Immunization Registry Association



**ANNUAL
REPORT**
July 1, 2002 –
June 30, 2003



Activity Highlights: July 2002 to June 2003

I. Providing Leadership

AIRA members, including over 100 public health professionals, computer consultants, managed care representatives, and community leaders, share resources and promote partnerships to advance the development and sustainability of immunization registries across the nation.

Programmatic Registry Operations Workgroup (PROW) Project

The purpose of the PROW project is to promote the use of immunization registries by immunization programs to increase the effectiveness of core immunization program components. The PROW, made up of representatives of AIRA, the Association of Immunization Managers (AIM), and the Centers for Disease Control and Prevention's (CDC) National Immunization Program (NIP), produced standards of excellence describing how registries can support vaccine management, vaccine-preventable disease surveillance, consumer information, provider quality assurance, service delivery, and vaccine coverage assessment. These standards were distributed to all immunization program and registry managers across the nation. The National Vaccine Advisory Committee endorsed the PROW's efforts at its February 2003 meeting. A PROW demonstration project was initiated in 2003 with 12 states and one large city working to implement the PROW standards. Lessons learned will be shared at the 2003 Immunization Registry Conference as well as in a report to be distributed widely next year. Bill Brand, AIRA Vice-President, continues to serve as Chair of the PROW Project. More information on the PROW standards may be found on AIRA's website at www.immregistries.org

National Immunization Registry Conference (IRC) — External Planning Committee

AIRA, along with partner organizations, Every Child By Two (ECBT), All Kids Count /Public Health Informatics Institute, and the Committee on Immunization Registry Standards for Electronic Transactions (CIRSET), worked closely with CDC/NIP to plan the 2003 IRC. Cindy Sutliff, AIRA Executive Director, and Amy Metroka, AIRA President, represented AIRA on the external planning committee.

National Immunization Registry Strategic Plan 2002–2007

In 2001–2002, AIRA and a broad range of other stakeholder organizations worked with the CDC/NIP to produce a strategic plan to reach the Healthy People 2010 national objective: to increase to 95% the proportion of children < 6 years old participating in a fully operational, population-based immunization registry. At the 2002 IRC, AIRA convened an Open Space Forum to engage conference participants in developing strategies to implement the focus areas of the plan: partnerships, provider participation, education, data quality, data use, privacy & confidentiality, technical capabilities, and integration. Conference attendees divided themselves into nineteen (19) task groups and formulated action recommendations for each focus area. A discussion outcome report was compiled and distributed to all conference participants before the closing of the conference. The outcome report was also posted on the AIRA web site at www.immregistries.org. AIRA Board members and committee chairpersons are now serving as stewards for each of the focus areas. Bill Brand and Therese Hoyle are stewards for partnerships, Sherry Riddick is steward for provider partic-

ipation, Ayesha Gill is steward for education, Barbara Canavan is steward for data quality and data use, Kim Salisbury-Keith is steward for privacy & confidentiality, Sue Salkowitz is steward for technical capabilities, and Ellen Wild and Kim Salisbury-Keith are stewards for integration. AIRA stewards are working collaboratively with the CDC/NIP stewards on advancing the implementation of the plan.

II. Providing a “Voice” for Registries

AIRA members participate in national workgroups, taskforces, and ad hoc committees to provide a voice for immunization registry stakeholders. These include:

Health Care Provider Workgroup (HCPWG)

Convened by the CDC/NIP to examine provider participation challenges and to make recommendations for increasing provider participation in immunization registries, the HCPWG includes representatives of medical professional organizations, health plans, AIRA, ECBT, and other stakeholders. The HCPWG is supported in its work by the AIRA Provider Participation Committee. This AIRA Committee, chaired by Sherry Riddick, is charged with collecting provider participation best practices from the registry community and developing resources to be used by state and local registries to increase provider participation in their areas. Sherry Riddick serves on the HCPWG along with Amy Metroka, AIRA President, and Barbara Canavan, AIRA Board Member.

Privacy & Confidentiality Committee

Bill Brand and Kim Salisbury-Keith have represented AIRA on both the CDC Privacy and Confidentiality calls and the Confidentiality Work Group (CWG). In 2003 there were five Privacy and Confidentiality conference calls. These calls were used to inform registry projects about current confidentiality issues and to facilitate discussion on a variety of related issues. Topics covered in the calls have included parental access to Hepatitis B immunization information, notification and data issues when patients legally become adults, smallpox and PVS consent issues, disclosure to schools under HIPAA, and input to the CWG review of notification timing and language requirements.

The Confidentiality Work Group (CWG) has met on a regular basis to develop the registry certification criteria for confidentiality based on the Community Registries Immunization Manual's Chapter on Confidentiality. The group has developed draft certification checklists for the application and on site review, as well as an evaluation process. Plans to finalize and pilot the work are underway.

Vaccine Safety and Registry Community (VASREC) Work Group

A collaboration of AIRA and the CDC/NIP, the VASREC work group serves as a forum for consensus development, problem solving, and feedback to CDC/NIP on issues, topics, and concerns relating to closer integration of vaccine safety information into immunization registries. This work group meets monthly and is open to members of the immunization registry community who are interested in bridging activities of the Vaccine Adverse Event Reporting Systems (VAERS) and immunization registries. AIRA Board member Terry Hughes serves on this work group.

Public Health Information Infrastructure (PHIN)

The CDC's Public Health Information Network (PHIN) is an effort to build a common framework for public health information systems across the nation that drives cost savings and rapid deployment. The first annual PHIN Conference was held by CDC in Atlanta, GA in May 2003. The conference brought together key stakeholder organizations and partners to explore how the PHIN can support and transform areas such as preparedness and response, integrated child health, and interaction with clinical medicine. AIRA member Amy Zimmerman, of the Rhode Island Department of Health, presented on lessons learned through building KIDSNET, Rhode Island's comprehensive, integrated, child health information system. To promote further exploration of the relationship of immunization registries to the PHIN, AIRA will be hosting a panel presentation on *The Role of Immunization Registries in the Emerging Public Health Information Infrastructure* at the 2003 IRC.

National Health Information Infrastructure (NHII)

A national health information infrastructure is needed to improve patient safety and quality, to rapidly detect bioterrorism and other health threats, and to enhance the efficiency of the health care system. AIRA participated in the The Department of Health and Human Services's conference in Washington, D.C., in July 2003 to begin development of a national action agenda for the NHII. The conference brought together key health information technology stakeholders to develop consensus for national action in eight key areas: research & population health; homeland security; consumer health; financial incentives; safety & quality; standards & vocabulary; architecture and privacy & confidentiality. AIRA co-sponsored this conference and sent Amy Metroka, AIRA President, and AIRA member Karen White, Minnesota Department of Health, as representatives.

Advocacy

AIRA Board of Director members continue to monitor key issues, trends, policies, and positions that may have an impact on immunization registries. Early in 2003, AIRA learned that the Centers for Medicare and Medicaid Services (CMS) proposed replacing five CPT codes for adult Hepatitis B vaccine with three "Q" codes. AIRA pointed out that this would result in a loss of code granularity, and movement away from standardization. Susan Salkowitz, AIRA Board member, helped convince CMS to withdraw the proposal. Ms. Salkowitz is now representing AIRA on a national workgroup examining proposed changes to CPT codes.

III. Furthering the Work of Local Registries

AIRA committees provide a forum for members that work in state and local immunization registries to exchange information and lessons learned. This year's committee activities included the following:

Education Committee

This year the Education Committee met via bi-monthly conference calls. Members researched and produced four editions of the *SnapShots* newsletter, which was distributed to over 800 people via broadcast e-mail. A special conference edition of *Snapshots* was distributed to all attendees of the 2002 IRC. This committee is now engaged in developing an education survey of AIRA members that will

help identify information needs of the registry community, specifically as they relate to the 2010 Healthy People Strategic Plan. Ayesha Gill of California, AIRA Board member, serves as Chair of the Committee and Editor of the *SnapShots* newsletter, which she and Katie Reed of New York State, jointly produce.

Technical Committee

The focus of the Technical Committee is to identify, share and promote methods and best practices to ensure data accuracy and completeness for immunization registries. The Technical Committee works in collaboration with CIRSET in their role to develop standards for electronic data exchange with registries. It has an ambitious agenda that includes projects to develop sample or model documents: business requirements, data quality improvement plans, data validation methods, data cleaning methods, and a HIPAA-compliant data security plan. Committee members are also presenting a Data Quality Workshop at the 2003 IRC. This peer forum will include presentations and discussions on: Making the Business Case for Data Quality; The Front Lines of Data Quality: How Different Registries Handle Data Quality Issues; Electronic Data Exchange; Best Practices in Data Quality; and Registry Certification Standards. Barbara Canavan of Oregon, AIRA Board member, and Steve Levy of Massachusetts, AIRA member, co-chair this committee.

Bioterrorism Committee

Formed during the 2002 AIRA Annual Meeting, the AIRA Bioterrorism Committee meets bi-monthly to discuss issues surrounding the use of immunization registries in bioterrorism preparedness. The Committee is co-chaired by AIRA members Karen Nikolai of Minnesota and Paula Soper of Maryland, and was formed to provide a forum for the exchange of experience, best practices and ideas for preparedness. The committee has assisted the CDC in improving the layout and flow of the smallpox vaccination form and has provided the CDC smallpox team with insight about the use of registries in bioterrorism preparedness and planning. A survey of AIRA membership was conducted to gather information about how registries were being used in smallpox vaccination clinics, and future plans for use of registries in smallpox vaccination programs.

Urban/City Registries Committee

This committee provides a monthly forum for representatives of Boston, Chicago, Detroit, New York City, Philadelphia, Texas and others to exchange information and engage in problem-solving on issues such as city-state relationships, provider participation, and data exchange with managed care organizations. Lennon Turner and Amy Metroka of New York City are the current co-chairs of this committee.

Provider Participation Committee

This committee is led by Sherry Riddick of Washington state, currently serving as AIRA steward for the provider participation focus area of the CDC/NIP immunization registry strategic plan. Committee members are collecting best practices and examples of outreach and marketing strategies used successfully by state and local immunization registries to increase provider participation. This information will inform the committee's recommendations to the CDC/NIP's Health Care Provider Workgroup (HCPWG), which is charged with developing a national

strategy for increasing provider participation. This committee is also developing resources and tools, including FAQs and a workbook, to assist state and local registries in planning effective marketing/promotion campaigns. This committee will offer a pre-conference workshop at the 2003 IRC entitled, *Building Provider Partnerships: Using Marketing Strategies to Promote Your Registry*.

IV. Developing Partnerships

Every Child By Two (ECBT) Managed Care Organization (MCO)/Registry Data Exchange Initiative

AIRA worked in partnership with ECBT on the implementation of an MCO/Registry Data Exchange initiative designed to increase the number of managed care organizations and registries exchanging data. A national advisory committee was established to guide the process, with AIRA Board member Therese Hoyle as its chair. To establish a baseline of activity, the committee designed and administered a survey of current MCO-registry data exchange by immunization registries across the country. Results of the survey will be used to determine strategies and next steps. Early indicators point to the need for capacity-building within the registry community for data exchange. The committee is also preparing a resource "how to" guide for both immunization registries and MCOs to facilitate data exchange. Aurora Oliva, AIRA Resource Developer, staffs the work of this initiative in collaboration with Amy Pisani, Executive Director of ECBT.

Committee on Immunization Registry Standards for Electronic Transactions (CIRSET)

AIRA has established a partnership with CIRSET to leverage the resources and expertise of both organizations. AIRA will work closely with CIRSET on promoting support and use of HL7 standards by AIRA members. AIRA will also provide administrative support to the work of CIRSET. The CIRSET web page will be co-located on the AIRA website, facilitating easy access for AIRA members to information on CIRSET's monthly teleconferences, and other activities and initiatives. CIRSET will continue to work with the AIRA Technical Committee on identifying issues and trends related to data quality, data use and standards, and on drafting strategies to address these issues. Dennis Michaud is the CIRSET Chair, and AIRA Board member Jeff Wehl serves as the AIRA liaison to CIRSET.

V. Providing Resources and Forums for Information Sharing

AIRA provides resources for immunization registries and facilitates information-sharing through the development and dissemination of tools and guides for registries, electronic transmission of information in a timely manner, and coordination of teleconference call meetings on specific issues and/or workgroup activities. Examples of activities this year include the following:

- Distributed the AIRA *SnapShots* newsletter quarterly via broadcast e-mail to over 800 people and posted it on the AIRA website.
- Distributed the CDC's *Immunization Works* bulletin via broadcast e-mail and posted it on the AIRA website.

- Developed and distributed the following AIRA tools and guides as resources for immunization registries in 2002-2003:

1. Do You Have a Fundraising Plan: A Fundraising Guide for Registries
2. Getting Started: A PROW Demonstration Site Start-Up Guide
3. PROW Standards of Excellence Document
4. What's Your Data Exchange Picture: A Survey of Immunization Registries Regarding Data Exchange with Managed Care Organizations
5. "What Knowledge and Best Practices Can Immunization Registries Provide to the Emerging Public Health Information Network?"

- AIRA coordinates monthly conference call meetings for the AIRA Board of Directors with the CDC/NIP, including AIRA partner organizations ECBT, All Kids Count/Public Health Informatics Institute, CIRSET and AIM. Calls focus on sharing information about implementation of the Immunization Registry Strategic Plan 2002 – 2007 and discussion of issues/hot topics that impact on immunization registries.
- AIRA has established Web-based "team pages" to facilitate the work of its committees and workgroups. Each AIRA committee and/or workgroup has its own "team page" that is password protected and allows its members to share information, post documents for review and comment, download documents, post meeting announcements and notes, and conduct discussions via a bulletin board.

VI. Providing Education & Training

Education and training opportunities coordinated by AIRA included the following:

- Two pre-conference workshops held at the 2002 Immunization Registry Conference in Philadelphia, PA.
 - a. HIPAA: The New Healthcare Landscape and Opportunities for Immunization Registries
 - b. INTEGRATED SYSTEMS PROJECT: Planning and Management Tools
- The outcomes of phase one of the PROW Project were presented at the 2003 Program Managers Annual Meeting. A lunch roundtable discussion was held following the presentation to discuss the implementation phase of the project. AIRA and AIM collaborated on this event. Bill Brand, PROW Chair and AIRA Vice-President, presented the outcomes and co-facilitated the roundtable discussion with Cindy Sutliff, AIRA Executive Director.
- Sue Salkowitz, AIRA Board member, delivered a presentation on the ECBT MCO/Registry Data Exchange initiative at the California State Immunization Information System annual meeting.
- AIRA collaborated with CDC/NIP on the preparation and delivery of a presentation to the National Vaccine Advisory Committee (NVAC) on the PROW Project. This presentation was designed to inform NVAC members about the standards of excellence for support of immunization program core functions by immunization registries,