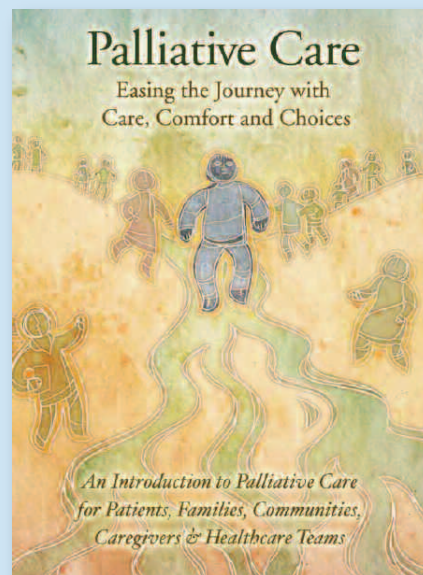


The Importance of Culturally Competent Palliative Care

Cancer is the leading cause of death for the Alaska Native people. Similar to many of the other underserved populations supported by the Intercultural Cancer Council (ICC), access to cancer care services is often difficult and fragmented. Palliative care is important to the Alaska Native people and yet the availability of palliative care and hospice services, taken for granted in many communities, is not available to most of the Alaska Native people and many American Indians. Remote communities, harsh weather, and few resources increase access problems. Traditionally, family members were cared for in the community from birth to death. The challenge of combining modern medicine with traditional ways is complicated. Too many elders nearing the end of life, often from chronic diseases like cancer, are flown from their small village to a large city like Anchorage, Alaska where they are clinically well cared for, but spend the remainder of their life away from families, familiar surroundings and traditional ways. Realistically, most of the Alaska Native people will never have access to resources like home health aides, visiting nurses, physical therapy and other supportive services.









A five-year NCI grant to help provide palliative care training for healthcare providers of the Alaska Native people offered an opportunity for many organizations, including ICC, to support annual palliative care symposiums that brought palliative care experts and Alaska healthcare teams together. The symposiums were successful and have transformed into international telehealth palliative care symposiums. However, the message of palliative care needs to be better understood by providers, patients, families and communities to support someone diagnosed with cancer. In these "high-technology" times, it is easy to forget that, in addition to pain and symptom relief medications, listening, helping-out, sharing good memories, are important to cancer patients and families.

(continued on page 2)



Editor's Note: A new 32-page booklet, written by Christine A. DeCourtney, *Palliative Care, Easing the Journey with Care, Comfort and Choices*, is available for \$4.95. Funds from the sale of the booklet go to reprint and develop palliative care comfort bags with much needed items that go home with the patients to the villages. To purchase the booklet, go to www.anthc.org.

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Pacific Regional Center Cancer Registry: Making strides to improve health in the USAPI

Effective programs and advocacy to control the entire spectrum of cancer require accurate baseline information and surveillance. The technology, resources and complexity required for meaningful cancer registries have been difficult to maintain in the U.S. Affiliated Pacific Island (USAPI) jurisdictions*, especially when superimposed on a base of inadequately trained and inadequate numbers of health workers.

Additionally, limitations in cancer diagnosis hamper accurate recording of information. Many cancer patients are still diagnosed at a very late stage, rendering the patient ineligible for off-island curative care. Most have no option except to remain at home to die, with inadequate access to palliative care. Recognizing the critical need for improved data quality

(continued on page 2)

Pacific Regional Center Cancer Registry *continued from page 1*

across the USAPI, the Cancer Council of the Pacific Islands (CCPI) has a long-term goal to develop functional cancer registries in each of the jurisdictions. The University of Hawaii (UH) Department of Family Medicine and Community Health received funding from the CDC National Program of Cancer Registries (NPCR) to conduct a cancer registry assessment in 2005-2006. This led to the policy decision to regionalize cancer registry functions, while allowing for jurisdiction-specific data and reporting needs. UH works with the jurisdictions to develop the Pacific Regional Central Cancer Registry (PRCCR). The PRCCR, housed at the University of Guam, continues to leverage resources and build partnerships upon existing NCI-funded efforts to improve the Guam Cancer Registry.

The first two years of the PRCCR cooperative agreement focused on training, policy development and addressing infrastructure challenges. With technical assistance and training, conducted in partnership with the Hawaii Tumor Registry and CDC, NPCR has developed a cadre of "home-grown" cancer registration professionals. Despite ongoing challenges, four of the six USAPI successfully reported 243 cancer cases diagnosed in 2007 and an additional 351

cases in 2008, to the CDC NPCR in January 2010. These cancer registries are helping to lead process improvement and serve as model efforts to leverage scarce resources in close coordination with local and regional policy makers and community members. We thank the CDC, NCI, ICC and all of the National Partnership for CCC for their continued commitment to reduce health disparities in peoples of the USAPI.

*Lee Buenconsejo-Lum, MD, Principal Investigator,
Pacific Regional Central Cancer Registry
Department of Family Medicine and
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* The USAPI is comprised of three Flag Territories, and the three Freely Associated States (FAS). The Flag Territories are American Samoa, Guam and the Commonwealth of the Northern Mariana Islands (CNMI). The Freely Associated States include the Republic of the Marshall Islands (RMI), and the Republic of Belau (also known as Palau) and the Federated States of Micronesia (FSM) which consist of Yap, Pohnpei, Kosrae, and Chuuk States.

This publication was supported by CDC NPCR Cooperative Agreement U58 DP000835. Its contents are solely the responsibility of the author and do not necessarily represent the official views of the CDC.

The Importance of Culturally Competent Palliative Care *continued from page 1*

The term "palliative care" is too often understood as "end-of-life" care, when it really begins when cancer is diagnosed. Palliative care is not about dying it is about living. It is care for the body, mind and spirit and not limited to a single location—it is a way of caring. Culture and tradition are important parts of palliative care. It is important for patients and families to share traditions with the healthcare team early in the disease journey. A good self-question is "What are the important parts of my culture?" or healthcare providers can ask "What is important about your culture and traditions that will help me provide better care for you?" This helps prevent misunderstandings

between patients and providers.

Finally, it is important to recognize that everyone is part of the palliative care team, not just the doctor and nurse. The hospital housekeeper, spiritual advisor, family members, teachers, community members and everyone else can help ease the cancer journey by realizing their important role no matter how small it may seem. In many cases, this is the only way underserved populations can receive the care and comfort they need and deserve when diagnosed with cancer.

*Christine A. DeCourtney, MPA
Cancer Program Planning Manager
Alaska Native Tribal Health Consortium*

From the Director

As Jim Williams, Chair of the Intercultural Cancer Council, notes in his article in this issue, the ICC is well on its way to developing community meetings in four regions for 2010. Much thought has gone into making the



Jay L. Silver, CPA

meetings as meaningful and productive as possible for the attendees. As mentioned by Jim, the content, as well as the participation, is being geared towards the participants leaving with new information to bring back to their own organizations and/or action steps to be taken.

The design of the community meetings in the regions is to have each of the attendees leave the sessions with good information as well as a plan on how to make a difference in their own community. Plenary sessions will be limited. Interactive workshops and "how to" sessions will dominate the meetings. So how can you and your organization benefit?

We are asking community-based and faith-based organizations to take a leading role in their regional meetings. If your organization would like the other attendees to learn about your activities, the regional meeting is the place to be. If your organization wants to be exposed to possible funding sources as well as providers of educational materials, the regional meeting is the place to be. If your organization is eager to present a workshop or have a lead position in the *Marketplace of Ideas*, just raise your hand and we'd love to have you be involved.

The meetings in the region are not about the ICC; they are about the grassroots organizations working on the community level. The ICC will serve as a facilitator helping local groups tell their story. We hope to make a firm connection between those with resources to provide and those groups needing resources. By example, in December, the ICC worked with two community-based organizations in Mississippi and

(continued on page 3)

Who's Who in the ICC

Dr. Sandral Hullett has served as CEO and medical director of Birmingham's Cooper Green Mercy Hospital since 2001, leading efforts to serve Jefferson County's



Dr. Sandral Hullett

uninsured and under-insured residents by providing quality, compassionate care regardless of a patient's ability to pay.

Under Dr. Hullett's leadership, Cooper Green has undergone massive building renovations,

upgraded equipment, and increased patient revenue all while working to raise the standard of care. Dr. Hullett brings to the hospital a deep commitment to the mission of serving the underserved as well as a sense of responsibility to the larger urban community. Her vision is for Cooper Green to lay the foundation for a healthier Jefferson County.

She has taken several steps to accomplish this goal:

- She has worked with staff physicians to create preventative care and education programs for widespread conditions such as diabetes and hypertension.
- She has encouraged the hospital's involvement in and creation of community health fairs and worked with partners such as the Jefferson County Health Department at these events to educate patients about preventive healthcare.
- She has reached out to other hospitals and established partnerships to better

serve patients with special needs, and she has renewed outreach efforts at Cooper Green's community health centers to better serve patients in the neighborhoods where they live.

Patients have noticed improvements at the hospital, thanks not only to \$32 million in renovations but also due to the enthusiasm of caregivers. In a recent national survey, 97 percent of patients at Cooper Green said they would recommend the hospital to a friend, giving it the best patient satisfaction score of any hospital in the state and one of the best in the country.

While the health of her patients always comes first, Dr. Hullett has also focused on improving the fiscal health of Jefferson County's public hospital, which has not only stayed under budget in recent years but has also begun to build a small reserve fund for future capital needs.

Dr. Hullett's accomplishments at the helm of Cooper Green have earned her recognition in Birmingham and beyond, including being named Business Person of the Year for 2009 by the *Birmingham Business Journal* and earning an honorary Doctor of Humane Letters from Tuscaloosa's Stillman College. She also served as chairperson of the board of directors for the National Association of Public Hospitals, 2006-2007.

Before coming to Cooper Green, Dr. Hullett was known for her work as a leader in rural healthcare. She served for 25 years as health service director at West Alabama Health Services, Inc. During that time, she published numerous research

projects, the majority dealing with prenatal issues among low-income black women and cancer control and prevention in rural areas. For her work in rural healthcare, Hullett earned an Exemplary Service Medal from the National Health Services Corps, a Women in Healthcare Lifetime Achievement award from Rutgers University, the Rural Practitioner of the Year award from the National Rural Health Association, and a Rural Leadership Image Award from the National Black Churches Family Council.

In the last decade, Dr. Hullett has shown that her commitment to improving healthcare for all people knows no geographic boundaries. She has motivated permanent, positive change at Cooper Green and has lifted the standard of care in Alabama's largest city just as she did for rural West Alabama.

From the Director *continued from page 2*

Alabama to invite other organizations to coordinate activities relating to disaster preparedness for vulnerable populations in their communities. One of the outcomes of the meeting is that the groups are now involved with several other organizations along the Gulf Coast and are joining forces to collaborate in their plans for readiness in the eventuality of another disaster in their area. We assisted in presenting the meeting, but the real work was done by the local organizations that were looking to establish new relationships. They came to the meetings and made things happen by being there.

We would very much welcome the opportunity to have you showcase your organization at the meeting in your region. All you have to do is raise your hand and say, "I want to be a part of this." Once your hand is raised, you'll be on the team. Please let me know how your organization would like to take a leadership role in the ICC's upcoming meeting(s) and you will be welcomed on board. Contact me at jsilver@bcm.edu and we can discuss how best to integrate your organization into the meeting in your region. I look forward to your allowing us to assist you.

Using Race to Reduce Incidence of Cancer

With colorectal cancer deaths 48 percent higher among African-Americans than among whites, HealthPartners Medical Group has become one of the "first medical organizations in the nation to use racial information about patients to customize their medical care," *The Minneapolis Star Tribune* reports.

Over the past six years, HealthPartners has voluntarily collected information about race from more than 90 percent of their patients. Clinics can use electronic medical records to identify patients by characteristics like race and age, and send electronic messages that advise black patients get screened for colon-cancer starting at age 45 rather than age 50, which is recommended for other groups. HealthPartners has also used the information for breast cancer screening, and sees this information eventually being used to customize care even further.

From the Chair

Bridging the Gap

As chair of the AICC, my major priority this year and next is to strengthen the ICC's National Network through a series of regional meetings.



COL (Ret) James E. Williams, Jr., USA

At the completion of the last national meeting in April 2008, we decided to take another path for the *Biennial Symposium Series on Minorities, the Medically Underserved & Cancer* (Symposium). The Symposium had been presented 11 times starting in 1987 with Washington, D.C. being the site of the last several. The decision was made to move the program to locales throughout the eight ICC regions and present it as meetings within the regions over a two-year period.

There will be four meetings in 2010 in the New York Metropolitan area, Chicago, New Orleans, and the Bay Area of California (San Francisco/Oakland) with four additional meetings in 2011. The reason for the change in approach following a successful run in Washington was to bring the program to the community and not have the community come to Washington. Presenting the Symposium on a local level will enable the ICC to showcase its programs, support its community-based member organizations and introduce the ICC and its local affiliates to potential regional and local supporters.

The regional meetings will address topics critical to the field of health disparities and cancer. In addition, the community meetings will be tailored to address the issues pertinent to that specific geographic area. Further, by bringing the sessions to the community, we are anticipating reaching a larger audience, as more people will be able to attend the meeting by limiting their travel costs. With reduced costs, the ICC will be able to accommodate more people. Dr. Dileep Bal is the chair of the regional meeting core planning group assisted by Drs.

Lovell Jones, Armin Weinberg and myself.

The common themes for the regional meetings are:

1. Engage at least one well organized CBO/FBO to host or co-host the meeting and identify local invitees.
2. Create a common agenda for a good portion of the meeting and local topics of interest for the remainder of the meeting.
3. Address specific topics, including ones that are relevant to the respective community in which the meetings are being held.
4. The meetings will be interactive (little in the way of formal presentations, much in the way of dialogue between all attendees).
5. Each of the sessions will be held at venues in the community where the participants reside and are comfortable for the attendees and easily reachable.
6. The invitees will be local. Plans do not include having attendees fly in to the meetings or stay overnight in a hotel. We anticipate 150 – 200 people per meeting.

Based on the amount of planned programming, the meeting will be structured to run from one to three days, depending on our local "host organizations" and how much they plan to be involved, both programmatically and financially.

Our programming will include a network luncheon with a speaker in which we honor a local community organization(s) and/or individual(s), along the lines of our Susan Shinagawa Leadership Award Luncheon, and an evening session that will include our *Marketplace of Ideas*. This concept is somewhat different from the traditional exhibit hall in that the *Marketplace* is designed for one-on-one interaction with the result being connections made which will be followed up immediately after the meeting. You may recall that at the last Symposium, we held the *Marketplace* where organizations with resources (government agencies, large national organizations, and others), met one-on-one with CBOs to determine what resources would be available from the

"resource provider" and what resources are needed by the "resource consumer." Programming the *Marketplace* in the evening will allow the community leadership to attend, not interfere with their daily work schedule and allow them to connect with partners who could provide resources to their local organization(s). If the meeting is planned for more than one day, a town hall event could also be held, in which dialogue could occur between community participants and professionals, addressing topics that are important to the respective community.

Our regional meeting programs provide an excellent opportunity for the ICC membership to participate in its planning and/or participation. ICC is your organization and we need your support. I challenge each member to get involved. Please assist in this project by contacting the ICC Executive Director, Jay L. Silver, at (713) 798-1069, or email jsilver@bcm.edu.

American Pain Foundation (APF) Unveils New Educational Initiative to Raise Awareness about Cancer Pain

To increase awareness of breakthrough cancer pain about people with cancer, caregivers and healthcare professionals, APF has launched the following new resources:

- **Survey results** on breakthrough cancer pain
- An **online toolkit** with information about the basics of breakthrough pain, tips for addressing pain management as an integral part of cancer care, treatment options, answers to commonly asked questions and much more
- A dedicated **online chat and interactive webinar**, *When Cancer Pain Breaks Through*, will offer more insight on breakthrough cancer pain
- A **planned roundtable discussion** with leading oncology and professional medical allies to help renew dialogue about the issue and spark action steps for improving care

For more information, visit www.painfoundation.org

Awards and Honors

Dr. Sanya Springfield Receives ESP Award for Health Management

Sanya Springfield, Ph.D., director of NCI's Center to Reduce Cancer Health Disparities (CRCHD), received the ESP Award for Health Management at the Alpha Kappa Alpha Sorority, Inc. 79th North Atlantic Regional Conference in Potomac, Maryland. Dr. Springfield was recognized for her countless efforts to further CRCHD's mission of eliminating cancer health disparities.



Mark Clanton, MD, MPH, Appointed to FDA Tobacco Products Scientific Advisory Committee

Mark Clanton, MD, MPH, former deputy director of the National Cancer Institute and current chief medical officer of the American Cancer Society's High Plains Division, has been appointed by the commissioner of the U.S. Food and Drug Administration (FDA) to serve as a voting member of the new Tobacco Products Scientific Advisory Committee. The committee was formed by the Family Smoking Prevention and Tobacco Control Act which grants the FDA the authority to regulate the production, marketing, and sale of tobacco products. The 12-person committee will "review and evaluate the safety, dependence and health issues related to tobacco products and provide appropriate advice, information and recommendations" regarding tobacco products to the FDA commissioner. Early in its agenda the committee is required to address important issues such as the use of menthol in tobacco products and the impact of dis-solvable tobacco products.



As the former deputy director of the National Cancer Institute (NCI) at the National Institutes of Health, Dr. Clanton held the senior-most executive responsibilities for the NCI divisions and offices responsible for cancer prevention, cancer control, and health disparities research. During

that time, he served as the U.S. representative to the International Agency for Cancer Research, a division of the World Health Organization.

Dr. Clanton practiced medicine in Texas for more than a decade and previously served as the chief medical officer for Blue Cross Blue Shield of Texas. He served as an American Cancer Society volunteer leader for 20 years before becoming a staff member and was president-elect of the national American Cancer Society prior to accepting the NCI position.

ICC Board Member Named Business Person of the Year

Sandra Hullett, M.D., CEO and medical director of the Cooper Green Mercy Hospital in Birmingham, Alabama, was named Business Person of the Year by the *Birmingham Business Journal*. (See Who's Who in the ICC on page 3).

ICC Co-Founder Saluted For His Decade of Achievements

The University of Texas M.D. Anderson Cancer Center's Division of Cancer Prevention and Population Sciences recognized **Lovell A. Jones, Ph.D.**, founder and director of the Center for Research on Minority Health and professor in the department of health disparities research for establishing the first congressionally mandated center focused on minority health. Jones was honored during the 34th Annual Meeting of the American Society of Preventive Oncology.

Jones was also recognized for his decade of achievements in the Center; his more than 25 years as a scientist, educator, collaborator, innovator, investigator, advocate, and leader in the field of health disparities and prevention, and his unrelenting dedication to helping minority and underserved populations.

ICC Board Member Named 2010 Jane Cooke Wright Lecturer

Amelie G. Ramirez, Dr.P.H., professor of epidemiology and biostatistics and director of the Institute for Health Promotion Research (IHPR) at The University of Texas Health Science Center at San Anto-

nio, has been named the 2010 American Association for Cancer Research (AACR) Minorities in Cancer Research Jane Cooke Wright Lecturer.

The lectureship annually recognizes an outstanding investigator who has made meritorious contributions to the cancer research field and who has, by leadership or example, furthered the advancement of minority investigators in cancer research.

Dr. Ramirez has spent more than 30 years directing programs focused on human and organizational communication to reduce chronic disease and cancer health disparities affecting Latinos, and trained more than 200 Latino students and investigators.

"I am extremely excited to receive this prestigious honor from the AACR," Dr. Ramirez said. "For more than two decades, one of my top priorities has been to increase the number and quality of minority doctors and researchers engaged in cancer control and prevention. As the U.S. continues to grow more diverse, it will take a more diverse medical, social and behavioral research field to successfully reduce and prevent cancer among these minority populations."

The Leukemia & Lymphoma Society Announces Co-Pay Funds Available for Myeloma Patients

Eligible myeloma patients will now be able to receive up to \$10,000 in support to help offset the costs of prescription drug co-pays and other insurance-related expenses. This increase is retroactive for expenses incurred from July 1, 2009, through June 30, 2010, and is available to new and currently approved patients.

Healthcare professionals may submit patient applications easily online through the established link to the Co-Pay webpage www.LLS.org/copay. Applications can also be submitted on the toll-free line with a Co-Pay specialist. Eligibility will be determined by medical and financial need. Co-Pay Assistance 877.557.2672

For more information on this and other LLS Co-Pay Assistance Program disease funds, please call 877-557-2672 or visit www.LLS.org/copay.

Calendar

CancerCare, in collaboration with Intercultural Cancer Council, offers free, telephone workshops on a variety of cancer-related topics. For details, and to register for a workshop, call 1-800-813-HOPE, or visit the *CancerCare* website at www.cancercare.org/connect.

- Apr. 16: Advances in the Treatment of Head and Neck Cancer
- Apr. 28: Breast Cancer and African American Women
- Apr. 30: New Advances in Bone Health for People Living with Cancer
- May 4: Understanding Treatment-Related Rash and Dry Skin
- May 5: Treatment Update on Thyroid Cancer
- May 18: The Eighth Annual Cancer Survivorship Series: Living With, Through and Beyond Cancer, Part II: Communicating with Your Health Care Team After Treatment: Making the Most of Your Visit
- May 20: Progress in the Treatment of Renal Cell Cancer
- May 21: CML: Current Perspectives and Treatment Update
- May 25: Breast Cancer Treatment Update
- May 26: Medical Update on Metastatic Lung Cancer
- June 11: Understanding and Managing Treatment Side Effects
- June 15: Breast Cancer and Hispanic Women
- June 16: Ovarian Cancer: Treatment Options and Current Perspectives
- June 17: Update on the Treatment of Metastatic Renal Cell Cancer
- June 18: Progress in the Treatment of Metastatic Breast Cancer
- June 22: The Eighth Annual Cancer Survivorship Series: Living With, Through and Beyond Cancer, Part III: Survivorship and Workplace Transitions
- June 23: Update on Lung Cancer from the 2010 ASCO Annual Meeting
- June 24: Caring for Your Bones When You Have Multiple Myeloma

July 13: The Eighth Annual Cancer Survivorship Series: Living With, Through and Beyond Cancer, Part IV: Survivors Too: Communicating With and Among Family, Friends and Loved Ones

End of Life Nursing Education Consortium (ELNEC) Geriatric Train the Trainer Program

April 29-30, 2010
 Free Registration for the first 100 eligible California nurses
 Westin Hotel
 Pasadena, CA
<http://www.aacn.nche.edu/elnec/>

Association of Oncology Social Work

May 12-14
 Phoenix, AZ
<http://www.aosw.org>

Oncology Nursing Society Conference

May 13-16
 San Diego, CA
<http://www.ons.org>

American Society of Clinical Oncology (ASCO) Annual Meeting

June 4-8
 McCormick Place
 Chicago, IL

National Lab Day A NIH Call to Action

Dear Colleagues,

I know we share a commitment to making sure that the kids in our communities get a solid science education and experience the excitement of what it means to be a scientist. That is why I am going to spend some time this April in a Washington, D.C. school doing hands-on science and talking about what makes science and discovery so cool to me. I ask you to do the same. National Lab Day is a new program that will make it easy for you to spend some time with a local middle or high school science teacher and her or his classroom. It's a bit weird that it's called a "day," since it really helps you link up with teachers who are asking for help at any time during the year. But that is good, because it gives you plenty of flexibility, and maybe you will want to build a continuing relationship with the school.

Most of us spend our days thinking about experiments and writing papers and may not realize that our 15-year-olds in the U.S. rank a disappointing 29th out of 57 countries in science achievement. Because of this, President Obama has said, "make no mistake: Our future is on the line. The nation that out-educates us today is going to out-compete us tomorrow." While we aspire to ignite a flame in the next generation of scientists, we may not have known where to start—until now.

We have created the NIH Science Education Nation Website, where you can learn more about today's schools, teachers, and students and how to establish effective partnerships:

<http://science.education.nih.gov/NIHSciEdNation>. When you are ready to join me in volunteering, sign up at <http://www.nationalabday.org>. (Please note that if the Web browser on your computer is Internet Explorer, it must be version 7 or higher for you to access the National Lab Day Web site.) Every day, teachers are requesting a scientist's advice or help. Let's work to ensure that none of them are disappointed.

Francis S. Collins, M.D., Ph.D. Director, National Institutes of Health

The Voice is published quarterly, on January 15, April 15, July 15 and October 15. Brief appropriate articles will be considered, space permitting. The content may be edited due to space constraints. We are always looking for Awards and Honors bestowed on our ICC members, as well as newsworthy notes.

The deadline for submission of articles to be included in the newsletter is the 15th of the month prior to the publication date.

Please email articles to the editor at bdechks@ix.netcom.com.

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