A message from Medical Director, J. Carey Jackson, MD, MA, MPH:

Health Disparities and Clinical Research

This year the Vietnamese remember the end of a long civil war. Many of us who are old enough know exactly where we were 40 years ago when we were told that Saigon had fallen. So many Vietnamese lives in the North and the South were lost in that war, so many French and then American lives were spent fighting that war. In the chaos of the immediate aftermath of the war, and then for years to come, there was an exodus of Vietnamese to the West. The U.S. received over 1,000,000 Vietnamese refugees when all was said and done, and then the Vietnamese-American community has grown from there. In the first decades after the war it became evident that there were a number of conditions disproportionately prevalent in the Vietnamese community; diseases such as tuberculosis, hepatitis B, liver cancer, and cervical cancer to name a few.

The Vietnamese were not the only survivors of civil war in Southeast Asia to flee to the U.S. in those years. The civil wars in Laos and Cambodia continued and generated sequential waves of refugees; Mhun, Mien, Khamu, Lao, and Khmer people formed new communities in U.S. as well. Many of these communities experienced the same health disparities as their Vietnamese counterparts. Over the past 40 years, a concerted effort has been made to address disease disparities in these communities by the CDC, NIH, and private foundations. In turn, funding a large number of special populations efforts across the nation who have dedicated themselves to work in specific refugee groups and on specific preventable or treatable conditions; investigators like Vicky Taylor in Seattle, Tung Nguyen and Steve McFee in San Francisco, Grace Ma in Philadelphia, Moon Chen in Sacramento, Roshan Bastani and Marjorie Kagawa-Singer in Los Angeles to name only a few. Their efforts have narrowed the disparities gap for some diseases like cervical cancer in some communities like the Vietnamese, while other communities experience persistently higher rates of these diseases. In the interim new groups are constantly arriving from Asia, Africa, and the Middle East.

Including small minority communities in research has always been a challenge. They are often excluded because of very small numbers, language barriers, and the relative expense of translating surveys, informed consent, and educational materials into many languages. The communities have also self-excluded because of suspicions that research is potentially exploitive or harmful. Sometimes they are simply ignored because no effort is made to engage the community and explain the rationale, methods, and potential benefits to community leadership in a comprehensible manner. If research leads to a nuanced understanding of disease states then systematically excluding small ethnic communities perpetuates the gap in our knowledge of subtle differences in genetic variation and ethnic communities compared to dominant populations and widens the health disparities for those minorities. To address this widening knowledge gap
concerted efforts have been made and must continue, to include newly arrived communities in research, and to reach out to marginalized communities.

In the 40 years since the fall of Saigon Hepatitis B has become a preventable and treatable disease. Yet this health disparity persists at much higher rates among recent arrivals from Asia, Africa, Latin America, and the Middle East. To be sure the immunization rates have greatly improved and we have learned a great deal, but there is a great deal more to learn to effectively intervene in the progression of disease among the growing mosaic of ethnic and linguistic groups in American life. In an article that follows Margaret Shuhart MD, Professor of Medicine and a hepatologist investigating Hepatitis B at the University of Washington highlights the new frontiers in research relevant to immigrant and refugee communities. Those of us providing care to immigrants and refugees know our patient panels and know who would be willing and able to participate in meaningful research. We can make an effort to include overlooked minorities in useful ongoing clinical trials that might help improve what we know about immigrant groups. Dr. Shuhart will identify the current questions being asked in trials across the country. Many of these trials would welcome minority community participants to improve our knowledge base and narrow the disparities gap.

Forty years now, and excellent progress has been made on some fronts, but not others. Hepatitis B marches on. Those of us who work with immigrants and refugees should this year resolve to renew our efforts to address health disparities like hepatitis in these communities in memory of those we have cared for who have fallen here and abroad to warfare and disease. Improving what we know about small minority communities will allow us to better serve them.

Carey

Hepatitis B Research and Immigrant and Refugee Communities

By: Margaret Shuhart, MD, MS, Director, Hepatitis and Liver Clinic Harborview Medical Center

Hepatitis B research traditionally has been underfunded, as diseases such as HIV and hepatitis C have been given higher priority by funding agencies. More recently, the NIH has established the Hepatitis B Research Network (HBRN), a group of 28 clinical sites across the US and Canada designed to address important clinical questions pertaining to hepatitis B in both children (7 sites) and adults (21 sites). Seattle has both adult and pediatric sites. Broad questions being asked by the HBRN include why some develop severe liver disease and liver cancer while others have inactive disease, how to improve the response to current treatments, and whether indefinite treatment is really required in those who have e antigen-negative disease. Most Southeast Asian/Asian adult persons have e antigen-negative hepatitis B, and many of these have active disease that places them at risk for cirrhosis and liver cancer. Despite the well-known benefits and excellent safety records of hepatitis B oral treatments, those with active disease are often reluctant to be treated, particularly if it is expected that such treatment will be lifelong. Identifying those for whom shorter duration treatment may be successful is critical if we are to engage more in treatments that can prevent the development of significant liver disease and liver cancer.

African-born individuals also have a high prevalence of hepatitis B infection. Through the HBRN studies, which to date have enrolled nearly 175 people from East and West Africa, we are able to explore risk factors for disease in these less frequently studied populations and include them in ongoing treatment trials. African Americans enrolled in our study, whether African or US-born, recently were found to be at increased risk for diabetes. Diabetes is known to further increase the risk for liver disease and liver cancer in people with chronic liver disease.

Additional HBRN studies in progress include the effects of hepatitis B on quality of life (in both children and adults), maternal knowledge of children’s hepatitis B infection and vaccination status, the impacts of alcohol and tobacco use on liver disease, the impact of pregnancy on hepatitis B activity, the role of the immune system in hepatitis B disease, and several others.

For more information about research studies, see:

- Hepatitis B Research Network (this site includes related links to CDC, clinical trials.gov, American Liver Foundation, Immunization Action Coalition, among others)
- Registered Clinical Trials (nationwide)
- Research contacts for local HBRN studies: Alycia Wolfstone RN, 206-744-7053, awolfstone@medicine.washington.edu and Dr. Margaret Shuhart, 206-744-7054, mshuhart@uw.edu
OF INTEREST ON ETHNOMED

Hepatitis - Selected Patient Education Materials

View materials in multiple languages and formats, including pamphlets and videos.

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Summer: Seasonal Safety Issues

Summer safety issues include heat-related illnesses, sun exposure, water safety concerns, and use of fireworks or concern about fire. Extremely hot weather can cause sickness or even death. View links to resources in different languages and formats, on these and other summer safety topics.

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This bilingual presentation is intended to be used by clinicians during discussion with patients about carbohydrates and blood glucose. It is culturally tailored to reflect foods commonly consumed by Somali Americans and includes photos of foods, meal comparisons, and portion sizes. Also with some information about managing diabetes during Ramadan. Authored by Jocelyn James, MD and Yetta Levine. Available as a PDF presentation and narrated slideshow.

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CALENDAR ITEM OF INTEREST

Doctors for Global Health General Assembly August 14-16, 2015

The theme for this 20th year assembly is Deconstructing the status quo: Building global health justice. Location: Seattle WA.

U.S. Conference on African Immigrant Health December 4-6, 2015

Save the date for the third annual U.S. Conference on African Immigrant Health. Sponsored by Office of Minority Health (OMH), Health Resources and Services Administration (HRSA) and EthnoMed. This year's conference theme is: Social Determinants of African Immigrant and Refugee Health: Rethinking Integration, Challenges and Empowerment. The conference will be held at the W Hotel in Seattle, Washington.

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ABOUT ETHNOMED

EthnoMed was founded in 1994 and is a joint program of the University of Washington Health Sciences Library and Harborview Medical Center in Seattle, Washington. EthnoMed grew out of another hospital program, Community House Calls, which was successfully bridging cultural and language barriers during medical visits, through interpretation, cultural mediation and advocacy with immigrant patients, families and communities. The website was created to reflect and support that experience. In recent years, our content has expanded to reflect many new communities that have settled in the Seattle area.

EthnoMed aims to address disparities in care through enhancing understanding between the medical culture and the culture of the patient. The program is grounded in relationships established with local ethnic communities and the providers who care for them. Our contributors come from a wide range of disciplines and experiences and include nurses, physicians, nutritionists, psychologists, academic faculty, medical interpreters, librarians, community
We invite you to share your knowledge and educational materials with the EthnoMed audience. Consider being a content contributor, collaborator or reviewer. Contact Us.

We hope that every newsletter edition will lead you to something helpful to your work. Please help us spread the word by forwarding this newsletter to a colleague or two, using the button below. Thank you!

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Plain Text

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