

IAHPC 2012 Annual Report



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Governance Issues: A complete list with all the names and titles of the directors can be found at the end of this report.

Changes to the Board Structure:

The board voted and approved several important decisions during 2012:

- Set to two the maximum number of consecutive terms that directors may serve in the board.
- Approved changes to the bylaws which give greater flexibility in the management of the organization and board meetings through electronic meetings.
- Approved the creation of the Chair – elect position
- Approved the creation of a “Rapid response” team of board members to enable to organization to respond within 48 hours to pressing situations that do not allow for a full board discussion. The rapid response team would be created from board members and it would change every time, matching the situation or need with the expertise of the members. Each team would have at least 5 members and would always include the Chair and Chair –elect.

Terms ended: The term for six board members ended on December 31, 2012: Zipporah Ali (Kenya), Michael Bennett (UK), Kin-Sang Chan (Hong Kong), David Currow (Australia), Gayatri Palat (India) and Scott Murray (UK).

Elections: Zipporah Ali, Gayatri Palat and Scott Murray were nominated and re-elected while Julia Downing from Uganda was elected as a new board member (all for the term 2013-2015).

Chair-elect: Lukas Radbruch was elected as Chair-elect for the period 2012-2013. His term as Chair will start in January 2014.

Fundraising

Grants and Donations: The names of all the donors for 2012 is listed at the end of this report. The organization received these important grants and donations during 2012:

- The Diana Princess of Wales Memorial Fund for \$325,927 to support palliative care post-graduate education and research education in Sub Saharan Africa
- Open Society Foundation for \$49,000 for core support
- Unconditional donation for \$25,000 from Grunenthal GmbH (Germany).
- In kind donation for \$120,000 from Google foundation for website positioning through the Google Ads program.

Financial Statements: (see Annex 1, 2 and 3)

Budget Statement:

General comments: The operation at the end of the year reflects a negative number because during 2012 we spent funds which were received during 2011 and can be seen in the cash accounts in the balance sheet.

Income: Overall we slightly exceeded our revenue target by \$10K or 2% more. A significant portion of the additional revenue was due to the increase in donations from members (over 300% of what we had budgeted), the increase in the IAHPC Press sales (sales of books and publications donated to IAHPC) and the returns on the investments (which are the Merrill Lynch funds in which most of our cash is invested).

We were able to only reach 24% of the expected donations from institutions and foundations (line 12). As a result of the changes in the economy, the number of foundations and institutions donating to global palliative care decreased during 2012.

Expenses: Overall we registered 4% or \$27,527 less than we had budgeted. The highest costs over budget were legal fees (due to a penalty fee we had to pay for including copyrighted data in Pallipedia – this matter was settled), bank fees (due to mistakes in the account information submitted by the grantees which resulted in double wire transfer fees), publication fees (for ISBNs and copyrights of Opioid Essential Practices and Opioid Essential Prescription Package publications) and website expenses (unforeseen expenses related to the new website and the development of the flash maps for the international directory and the Opioid Price Watch project).

Profit and Loss Statement:

All the expenses are split in two categories: conditioned and unconditioned. The revenue from our operations is used to pay the unrestricted expense, while the revenue from grants is applied to the conditioned expenses.

Total revenue for the year was almost \$660,000. Of these, \$565,230 were restricted, or almost 90%. The difference of \$120K with the revenue the budget statement is due to the in-kind donations (most of which are from the Google Foundation) as the budget only represents cash, while the P&L represents both cash and in-kind donations.

Account 4545 reflects the \$49K grant from the Open Society Foundation for core support and the funds from the DPWWMF grant which were allocated to cover administrative expenses.

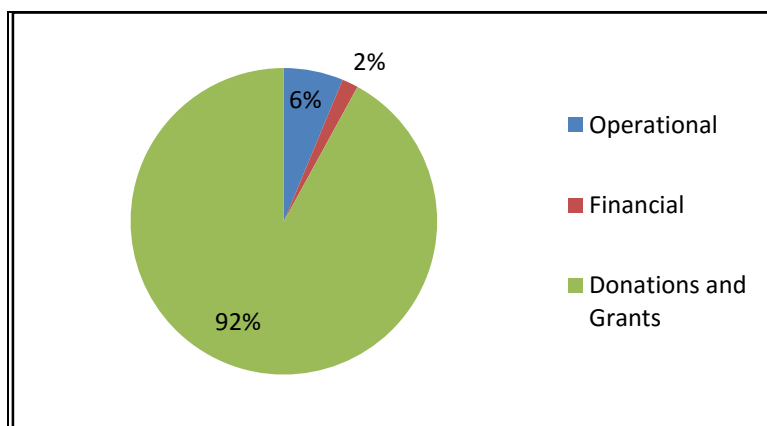
The restricted Traveling Scholarship (acc 4510) includes the funds which have been given to grantees through the DPWWMF-IAHPC program, plus an accrued expense which is reflected in the balance sheet as a liability (payable to still undesignated grantees).

Balance sheet:

Our total assets (cash in BOFA and investments in Merrill Lynch) add to almost \$276,000. Most of our assets are cash and money market funds plus \$6K in our office equipment (computers and monitors). We depreciate these in 3-4 years, depending on the model and type. This is reflected in account 1300 and 1310.

The liability in acc 2000 includes the payment which was made after the end of the year to EBSCO to cover the cost of the access to the CINAL database. The accrued expense mentioned in the P&L paragraph is reflected as a liability in acc 6510. In the case of the DPWWMF this liability does not have a fixed time period but has gradually decreased and will continue to do so as we allocate more grants in 2013. It is expected that the total grant will be allocated entirely by the end of 2013.

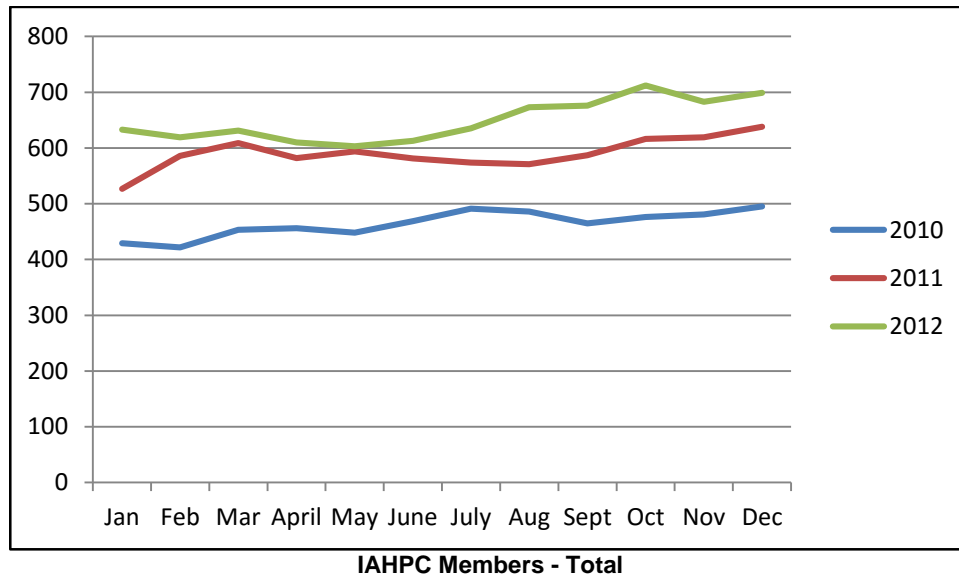
The percentage income distribution by category during 2012 is represented below:



Compared to 2011, we increased our operational revenue slightly in 2012 (\$38K vs. \$37K respectively). The operational revenue is reflected in account 5000 and 51000. However it decreased as a proportion in overall income due to the increase in grants and donations.

Membership Program:

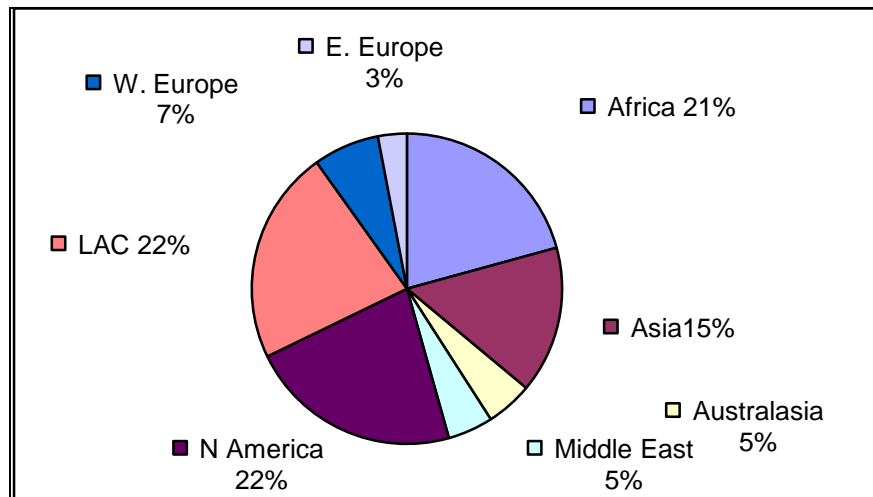
Members' Profile: By the end of 2012, there were 699 members compared to 638 and 495 for that same month in 2011 and 2010 respectively, demonstrating that the strategies to increase membership which were implemented during 2011 and continued in 2012 are still successful. These are described further below.



Numbers also indicate that there is an increasing trend in members from Africa and Asia and North America. All other regions, (Middle East, Latin America, Western and Eastern Europe and Australasia) continue equal or slightly less members than in previous years. Membership from Latin America in that region is less steady and changes are reflective of the year when the Latin American Association for Palliative Care Congress takes place, when individuals tend to renew or join as new in the IAHPC booth at the congress (see figure below).

An important and significant fact is that the same number of individuals are renewing as those who are signing up as new members. In previous years, more than 60% of our members did not renew. This new trend may be the result of the additional benefits we are offering of discounts and the access to journals.

In terms of percentage, Latin America and North America are the regions with the highest proportion (22%) followed by Africa with 21%.



Sixty-six percent of our members are physicians, while 30% have other health care professions. The remaining 4% are institutions.

Membership Strategies: The following are the membership strategies adopted in 2011 and continued in 2012:

- *50% discount from the regular membership fee* to those who join during selected congresses: This offer is given to participants in congresses where IAHPC participates with a booth and traveling scholarships. It was implemented during the AAHPM in Vancouver and the EAPC Congress in Lisbon in 2011 and was later extended to groups of individuals who join through a single lump payment. The offer will continue for other regional congresses, as well as to groups of individuals that may join IAHPC through one of our Board members.
- *Members' Month*: October was designated as the Members' Month and two prizes were given in two categories:
 - Loyal members (randomly select a current member who has been consecutive member for at least two years), and for bringing new members. Prize was given to Dr. Bishnu Dutta Paudel, from Nepal.
 - Members who bring the most members. Prize was given to the Leadership Development Initiative at San Diego Hospice. LDI brought 30 new members to IAHPC.

Both winners received an iPad as a prize.

Traveling Scholarship and Fellowship Programs

Through the Traveling Scholarship we provide financial support to regional and local leaders from developing countries, to help them pay for their travel to an international meeting or congress. Scholars apply online through our website and a group of members from the board discusses and decides on the application and the amount granted to each grantee. In 2012, we awarded 43 Traveling Scholarships.

Through the Traveling Fellowship, we provide financial support to individuals who are invited to teach and train other health care workers in developing countries. Traveling Fellows should have a significant amount of experience in palliative care and sufficient expertise to be able to teach to students and others. In 2012, we awarded 5 Traveling Fellowships.

Diana Princes of Wales Memorial Fund – IAHPC Bursaries

The objective of the bursaries is to build, improve, and advance palliative care in sub-Saharan Africa.

Individuals living and working in Ethiopia, Kenya, Malawi, Rwanda, South Africa, Tanzania, Uganda, Zambia and Zimbabwe are eligible to apply for these bursaries. The program was launched in September of 2011.

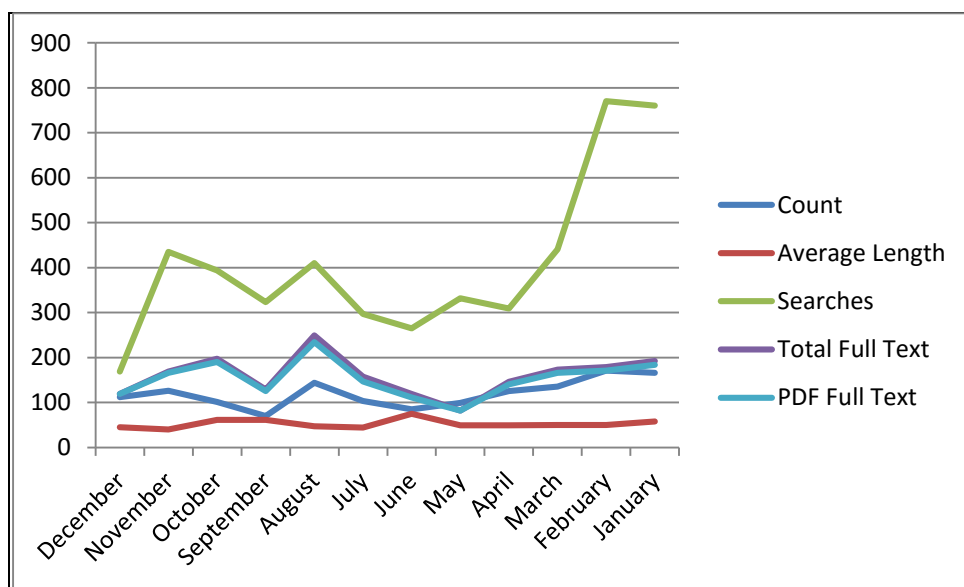
Bursaries are being awarded in two categories:

- Post-graduate qualification courses in palliative care. Courses need to be in institutions which are government accredited and academically affiliated and for post graduate level leading to a certified and government recognized formal degree (ie Distance Learning Diplomas, MSc/MPhil).
- Research courses on basic research and methodology, including study design, statistical tools, statistical analysis and applicability, writing grant applications for research and preparing a paper for publication in peer-reviewed journals.

In 2011 we awarded 42 grants in total of which 30 were for post-graduate qualification courses and the remaining for training in research in palliative care. In 2012 we awarded 76 grants of which 52 were for post graduate courses and 24 for training in research in palliative care.

Strategic Plan update: The following is a list of the main projects designed and commissioned during the strategic plan 2008-2012:

- *EBSCO- CINAHL – Access to Journals.* A total of 4,905 searches were done in of 2012, while by the end of March 2011, a total of 6,394 searches were performed. We are unaware of the reason behind this decrease in the utilization of this resource.



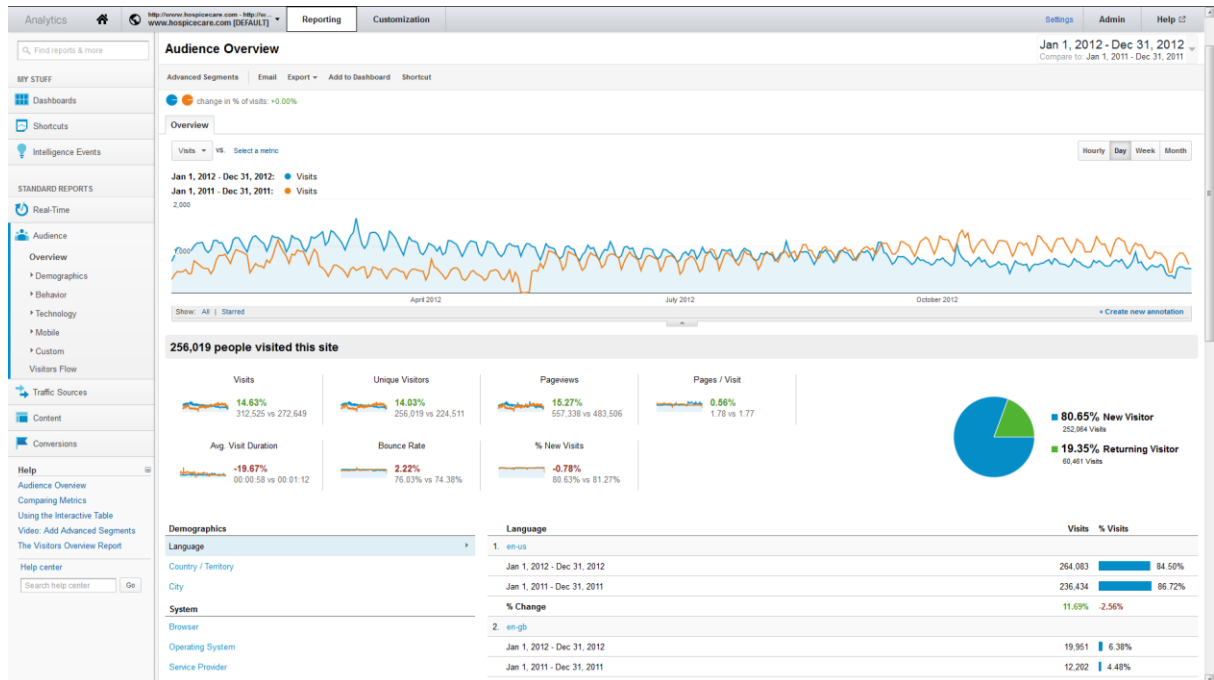
- *IAHPC List of Essential Practices in Palliative Care:* Members of the working group include the following board members: Michael Bennett, Scott Murray, Peter Hudson, Eduardo Bruera, Derek Doyle, Florian Strasser, Roberto Wenk and Liliana De Lima and two external advisers: Clara Granda-Cameron and Julia Downing. Additional advice, recommendations and comments were provided by Gian Domenico Borasio, David Currow, Faith Mwangi-Powell, and M.R Rajagopal. A three phase study was designed which included a Delphi process and a ranking survey with representatives from 25 palliative care organizations. The practices with the highest scores were

selected to form the list. Forty-nine practices were selected and ranked. "Evaluation, Diagnosis and Treatment of Pain" scored the highest (352 points). After analyzing the results, the WG arranged the resulting practices in 4 categories: Physical care needs, Psychological /Emotional /Spiritual care needs, Care Planning and Coordination, and Communication.

This project is finalized and a report published and disseminated through the IAHPHC website and in the following peer review journal: De Lima L, Bennett MI, Murray SA, Hudson P, Doyle D, Bruera E, Granda-Cameron C, Strasser F, Downing J, Wenk R. International Association for Hospice and Palliative Care (IAHPC) List of Essential Practices in Palliative Care. *J Pain Palliat Care Pharmacother.* 2012 Jun;26(2):118-22.

- *IAHPC Opioid Essential Prescription Package (OEP)*: The aim of this study was to determine by consensus the components of an opioid essential prescription package (OEPP) to be used when initiating a prescription for the control of moderate to severe chronic pain. Palliative care physicians (n=60) were sampled from the IAHPHC membership list to represent a range of countries of varying economic levels and diverse geographical regions. Using a Delphi study method, physicians were asked to rank preferences of drug and dosing schedule for first line opioid, antiemetic and laxative for the treatment of adults with chronic pain due to cancer and other life threatening conditions. Published in *Journal of Palliative Medicine Open Access*. Ref: 46. Vignaroli E, Bennett MI, Nikolaichuk C, De Lima L, Wenk R, Ripamonti CI, Bruera E. Strategic Pain Management: The Identification and Development of the IAHPHC Opioid Essential Prescription Package. *J Palliative Med.* 2012;15(2):186-191. Available in <http://cl.exct.net/?qs=6d889d03e282742055597de69b54412f42e66930d3b810dc9a5e242d6ca2cbe1>
- *Opioid Price Watch*: This project was initiated in December in partnership with the World Health Organization (WHO) with funding from the US Cancer Pain Relief Committee. The objective of the project is to increase awareness about the affordability (or lack of) of opioids around the world. It will be implemented through a flash map displaying the different retail prices of opioids in pharmacies throughout the world. The pilot project to test the data collection forms and the flash map was initiated at the end of 2012 and will be finalized in 2013.
- *Opioid Workshops in Central America*: One workshop on opioid availability and accessibility was developed and implemented in 2012 in February 2012 in Quito for Ecuador, Bolivia and Venezuela. Participants to the workshop included the national competent authorities of each country, pharmacists and pain and palliative care physicians. Participants from each country identified and developed an action plan to eliminate barriers which interfere with legitimate access to the medications. The workshops are developed in collaboration with the Pain and Policy Studies Group at the University of Wisconsin and the Access to Controlled Medicines Program at the World Health Organization in Geneva. The workshops were funded with grants from the De Lima Bohmer Foundation in Colombia and the Open Society Foundations in New York. In-kind support was received from the industry. Follow up strategies and plans to continue providing technical support to the countries are in place.
- *Website*: One of the recommendations resulting from the 2008 strategic plan was to develop a new website. Our current website was developed using structures which are now outdated when there were limited choices. The website has been built over the past 12 years using patches in different platforms, which poses a great security risk: our site has been hacked twice - once in 2010 and once in 2011, paralyzing our operations. In addition, we had two minor hacking attempts during 2011 and one in this year. A working group of board members was formed to help us advance this process. The members of the working group include Roberto Wenk, Roger Woodruff, Yvonne Luxford, William Farr and Bernard Lapointe.

The new website was launched in August 2012, after two years in the making. We registered a total of 264,083 visits in 2012 compared to 236,434 visits in 2011. Of these, almost 81% were new visitors. In the graph below the blue line represents the visitors in 2012, the orange for 2011. The number of unique visitors increased by 14% from 272,649 to 312,525. However, the number of new visitors decreased slightly.

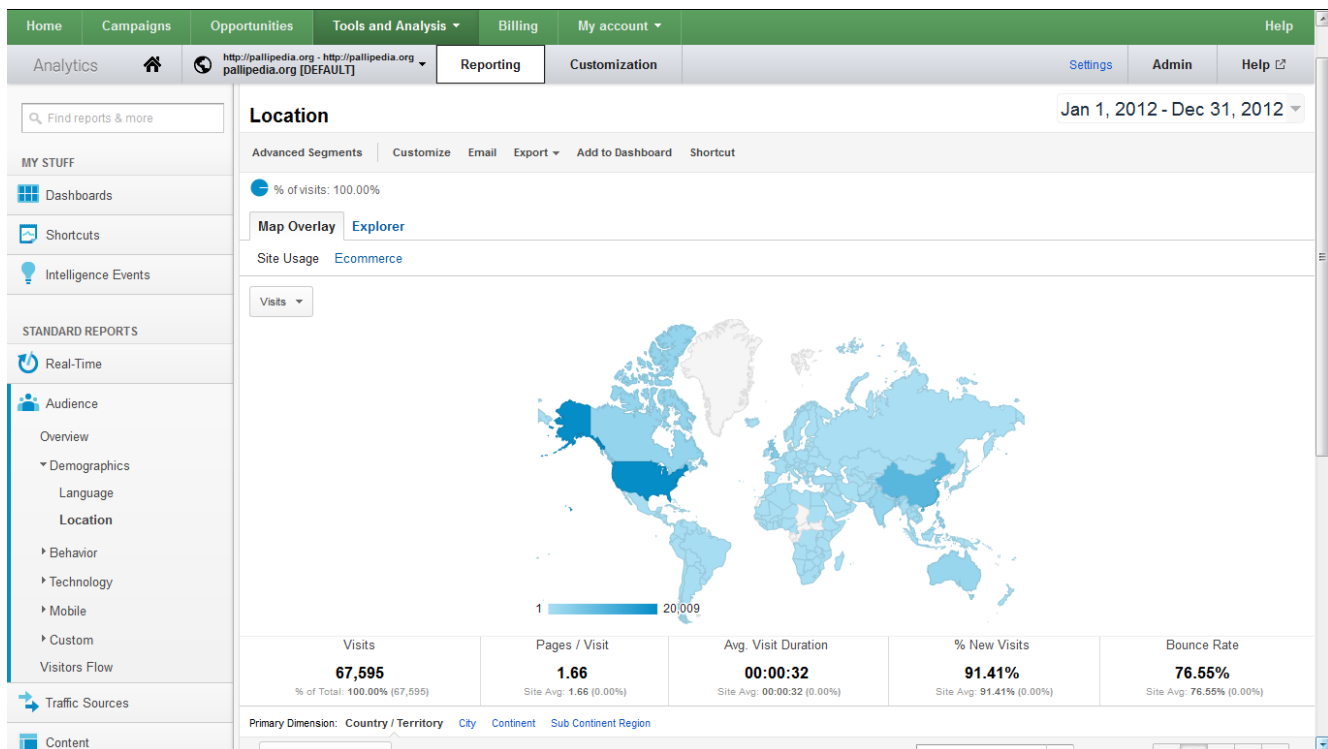


The data indicates that most of our visitors are based in the USA (122,000) followed by the UK (44,220) and Canada (15,404). In total people from 201 different countries visited the IAHP website in 2012. However, it also indicates that we have users in almost all the countries of the world with only a few exceptions.

- **Pallipedia:** Free online palliative care dictionary nurtured by the international community, under the auspices of IAHP. The objective of Pallipedia is to develop and continuously grow a high quality, objective educational resource for the global Palliative Care community. The dictionary is housed in www.pallipedia.org

Pallipedia currently has 929 terms and 1,092 definitions (several terms have more than one definition). The team at Pallium India, under the leadership of MR Rajagopal started working in the dictionary in the second semester of 2012 by suggesting, identifying and selecting definitions and terms. Their work has greatly improved the dictionary and we will continue working with them in this project. By the end of 2013 we hope to have reached more than 1,200 terms.

The map below shows the utilization data for Pallipedia: In 2012 we registered a total of 67,595 visits to the website, compared to 50,571 for 2011, most of which were from the USA (29.6%) and China (14.6%), followed by the UK (7%), Philippines (4.3%), Canada (4%), India (3.6%) and Australia (3.2%). A significant percentage (28%) is of unknown origin.



Newsletter

The Newsletter continues to be an extraordinary source of information about IAHPC, our programs and grant opportunities as well as a source of information about program development, events, and other news from the global palliative care community. 2012 marked the 16th anniversary of the NL.

The individuals responsible and contributors for the Newsletter are:

- Roberto Wenk is the editor and William Farr senior editor. Dr. Farr assumed this role for 2012, and previous to that he was editor for 15 years, as a service to the organization.
- Roger Woodruff writes the palliative care book reviews
- Liliana De Lima is responsible for collecting the information and sending it to the editor.
- Board members contribute a monthly piece to the newsletter.
- Danilo Fritzer, the IAHPC webmaster is responsible for layout and dissemination.

The number of subscribers by December 31st, 2012 was 8,972.

Collaboration with other Organizations

As in previous years, the IAHPC has a policy of collaboration with international and regional organizations to support and advance palliative care globally through its programs or advocacy initiatives. The following is a brief summary of some of the collaborative projects the organization did during 2012.

European Association for Palliative Care (EAPC): IAHPC providing scholarships to the EAPC Research Congress, to ten participants from developing countries.

Latin American Association for Palliative Care (ALCP): Provided technical assistance to the organization in developing its management and governance structure and Liliana De Lima is a member of the task force of the ALCP Atlas on Palliative Care for Latin America. IAHPC also participated in a meeting

convened by the ALCP in November 2012, in Lima, Peru to develop palliative care to monitor palliative care. A report with the developed indicators will be published in 2013.

Pain and Policy Studies Group – University of Madison/WHO Collaborating Center: Collaboration and partnership in the Opioid Availability and Accessibility workshops in Quito, in February 2012.

The Institute for Palliative Medicine at San Diego Hospice: Collaboration and participation in the International Leadership Development Initiative (Cohort 2).

World Health Organization (WHO): IAHPCC completed and submitted the application for formal relations with WHO during 2012 (with a positive decision by the WHO Executive Committee in January 2013). The formal relations with WHO include the development and implementation of regional and national workshops on access to and availability of opioids and other controlled medicines, funding for Spanish translation of the *Paediatric Chronic Pain Guidelines* and the *Ensuring Balance in national policies on controlled substances: Guidance for Availability and Accessibility of controlled Medicines*, collaboration in the dissemination, implementation and use of the *WHO – INCB Guidelines on estimating requirements for substances under international control*, collaboration in the development and implementation of the *Opioid Price Watch (OPW) project*, development of the *List of Essential Practices in Palliative Care*, a list of the palliative care skills and competencies required to perform the Essential Practices for primary care level in low and middle income countries and development of a palliative care model curriculum for education and training for primary health care workers in low and middle-income countries.

Worldwide Palliative Care Alliance (WPCA): Collaboration in the promotion and dissemination of the World Hospice and Palliative Care Day. LDL is a member of the WPCA advocacy group.

IAHPC BOARD OF DIRECTORS – 2012

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IAHPC Donors – 2012

Over \$100,000

Diana Princess of Wales Memorial Fund
Google Foundation (in-kind)

Between \$20,000 and \$49,999

Open- Society Foundation
Grunenthal GmbH

Between \$1,000-\$19,999

Carlos Calbarcas and Mrs. Maricel Marquez
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Between \$300 and \$999

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Between \$100 and \$299

Independent Charities of America
Furio Pietribiasi
Charles and Conni Puckett
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Up to \$99

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