

## FROM THE PRESIDENT

--John Sargent



AFTA continues to grow and thrive. I want to welcome Jackie Hudak as the new Editor of the *AFTA Update* and thank her for her willingness to serve in this capacity. I have been excited by the enthusiasm that she is bringing to this role. It is indeed special. You have recently received the latest issue of the *AFTA Monograph*. I hope you have had a chance to read the compelling articles on our social justice practices with a focus on theory and training. I want to commend Jane Ariel, Pilar Hernández-Wolfe and Sarah Stearns for their efforts in putting the issue together. I also want to recognize and thank Laura Forman for her work over the last several years in overseeing the *Monograph* and in enhancing the scholarliness and excellence of the *Monograph*. This has been a labor of love

for Laura and she has done this with grace and thoughtfulness. I am very pleased that Melissa Elliott has agreed to become our new Publications Chair. You are probably aware of her sensitivity and integrity. I look forward to her work on the *Monograph* with future issue editors.

You know from my previous communications that I am encouraging regional meetings and get-togethers of AFTA members locally throughout the year. I do believe that this is a way for members to be with one another and make important connections. I also expect that this will be a way for members who are not able to attend the Annual Meeting in a particular year to be an active part of our organization. Members have begun to plan these meetings in several locations. We will let everyone know about these meetings as

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## WHAT CAN LORENZO'S OIL TEACH US ABOUT SOCIAL MEDIA?

-- Gonzalo Bacigalupe

This article is a modified version of a blog entry<sup>1</sup> I wrote for the official blog of the Collaborative Family Health Association. I began collaborating with this initiative as a way of sharing my thoughts and ideas on the subject of digital technologies. A blog allows the sharing of evolving ideas and the possibility of entering a collaborative dialogue that later on may result in further publications or research projects. Since digital technologies advance at a really fast pace, waiting for a conference meeting or the conversation that may occur as a result of a peer review submission can be limiting; the blog provides a terrific outlet for

an asynchronous conversation that is not circumscribed by geographical distance.

Many of my colleagues and dear friends are still trying to understand what this whole social media buzz is all about. They may not have a Twitter account or may wonder how they could use LinkedIn; Facebook still confuses them. They often ask me what is so fascinating about "this thing". They wonder what else they could do with their recently acquired iPhone

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## 2010 CONFERENCE: BOULDER, CO

--Corky Becker, Program Chair

The Program Committee for the AFTA 2010 meeting in Boulder Colorado has worked very hard to put together a very exciting program integrating public issues and private lives. The topics covered range broadly from meeting the cross cultural challenges necessary to diminish mental health disparities, supporting resilience in youth at risk, innovative approaches to working with couples, connecting social justice with training and therapy, working with military families and violence related to war and trauma, models of treatment integrating post modern ideas and on the ground realities, ambiguous loss and grief, approaches to working with women using leadership opportunities, and more. There are interest groups on training, research, community oriented services, spirituality, mindfulness, and family and couple therapy. The forums offer opportunities to connect with people providing services in the Boulder community, to think together about social justice and training, and family policy. The AFTA community has a tradition of trying to get it right, by treating people with the imperative of working for human rights and social and economic justice, and finding ways to make a difference in peoples' lives in both the broadest and most immediate contexts. We hope to see you in Boulder when the beautiful mountain foothills come to life with new green and offer spectacular views for your nourishment, and where we come together for community and learning. Please join us and bring your colleagues.

Program Committee:

John Lawless, Jane Ariel, John Rolland, Pilar Hernández-Wolfe, Michael Ungar,

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<sup>1</sup> [http://www.cfha.net/forum\\_thread.php?t=93](http://www.cfha.net/forum_thread.php?t=93)

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besides making phone calls<sup>2</sup>. “What is in there and why invest my precious time?” “With email, I have enough!” they tell me.

For a long time, my initial response was to start describing some of the social media tools—maybe show them some with my laptop or smartphone. In a few minutes though, my colleague would be looking at me in the same way I sometimes watch an Apple Store adolescent “Genius” figure out in two swift mouse movements what to do with my puzzling hardware or software problem. Clearly, explaining the tool does not do the work, and in fact there are wonderful guides for both beginners and more proficient users<sup>4</sup>.

My responses have evolved, and presently I am more curious about what informs such comments and questions. I am trying to understand more, and to engage in a conversation about change – and the difficulty we may have in imagining what this new technology means. For instance, a few years ago, what was real and virtual had clear boundaries: today, information technology developments make those boundaries blurred. We are experiencing a breaking down of the real and the virtual (i.e., Jordan, 2009)<sup>5</sup>. I may also talk about some fascinating ongoing projects like PatientsLikeMe<sup>6</sup> or new developments in monitoring health via mobile phones<sup>7</sup>. I have accepted the notion that even if one overcomes some of the skepticism and fear (at times), there are still a lot of barriers for those who were educated without computers and the internet (including me, someone who wrote his 300 page master thesis with an Underwood typewriter).

A metaphor that has helped me lately is to ask people in these conversations to think

2 An example of how to smartphones in health care: <http://www.fastcompany.com/blog/lydia-dishman/all-your-business/8-great-medical-apps-healthcare-professionals>

3 [www.apple.com/retail/geniusbar](http://www.apple.com/retail/geniusbar)

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5 [http://findarticles.com/p/articles/mi\\_qa3800/is\\_200907/ai\\_n32129106/?tag=content;coll](http://findarticles.com/p/articles/mi_qa3800/is_200907/ai_n32129106/?tag=content;coll)

6 [www.patientslikeme.com](http://www.patientslikeme.com)

7 [www.fastcompany.com/node/1387814/print](http://www.fastcompany.com/node/1387814/print)

about the widely acclaimed film *Lorenzo’s Oil* (George Miller, 1992). Based on a true story of the Odone family, the film tracks Augusto and Michaela’s relentless search for a cure for their son Lorenzo, who was diagnosed with a very rare disease (ALS). We learn about the lack of collaboration and dismissal among doctors, support groups, and scientists as the parents attempt to find a cure and provide maximum hope for Lorenzo. The Odones were on their own and isolated, the perfect plot for a Hollywood script: individuals overcome great adversity and triumph.

In the mid 1980’s, when communicating via computers was not even close to a mainstream activity, primitive forms of social technologies were still only at reach for a few. Even though the Odones found a scientist willing to work with them, it was at a tremendous emotional, familial, and financial cost—something few families could afford.

How would the Odones’s plight have been different if they had had access to modern social media technology? How would those events have played out in this decade? They could have joined many of the health related social networks available today to ask physicians questions, allowing for quick-second consultation and cross-referencing (i.e., MedHelp<sup>8</sup> or Patients-LikeMe). If they wanted to advocate for policy changes or funding, they could have joined a health care activist social network like WeGoHealth<sup>9</sup>. They may have organized through a standard Facebook group or an ad-hoc tailored Ning social network, joined many of the rich health care communities in Twitter, set up a blog, uploaded video and photo updates via Flickr and/or YouTube. Or they would have benefitted from a combination of these tools.

The revised story may not have made a great film plot, but it would have elicited enormous resources and resilience, a richer collaborative process that advanced their child’s health care, advanced clinical research, mobilized policy makers, and

8 [www.medhelp.org](http://www.medhelp.org)

9 [www.wegohealth.com](http://www.wegohealth.com)

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they occur. We will also make sure that everyone learns from those who have meetings how to build and hold successful regional meetings.

Finally I want to invite you to come to our Annual Meeting in June in Boulder, Colorado. Corky Becker has done a tremendous job in organizing what looks to be an outstanding meeting. Please look at Corky’s report in this *Update*. You should receive the Program shortly with the details of the meeting as well as information about registration and arranging hotel accommodations. You also will want to plan to attend the Special Event this year for an opportunity to be with AFTA colleagues in the mountains near Boulder. I sincerely appreciate all of Corky’s efforts and thank her, Jerry Gale, David Wolsifer and the Program Committee for all of their work in putting the meeting together. It will be a great time for all of us.

See you in Boulder. Come. Learn, share conversations with colleagues and have a truly memorable time.

much more. Empowered patients, therefore, are not anymore just patients who are able to talk assertively to their doctors, but those who are positioned at the center of a network of collaborators.

The Odones and other families with a boy diagnosed with ALS (it only affects boys) would not have to make much effort to find advice, even in mainstream media. Today, indeed, social media facilitates the fruitful remembering of Lorenzo’s life via the Myelin Project.<sup>10</sup> This has grown to a project that aims at accelerating multinational research in a collaboration that now includes the same clinical and research establishment initially at odds when the Odones first began looking for a cure.

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[www.MyelinProject.com](http://www.MyelinProject.com)