Unless otherwise noted, the publisher, which is the American Speech-Language-Hearing Association (ASHA), holds the copyright on all materials published in Perspectives on Telepractice, both as a compilation and as individual articles. Please see Rights and Permissions for terms and conditions of use of Perspectives content: http://journals.asha.org/perspectives/terms.dt

The International Use of Telepractice

Robert J. Shprintzen

The Virtual Center for Velo-Cardio-Facial Syndrome, Inc.

Manlius, NY

Disclosure: Robert J. Shprintzen is affiliated with the Virtual Center for Velo-Cardio-Facial Syndrome, Inc., which is described in this article in order to discuss the application of telepractice internationally. This center is a nonprofit corporation, and although it is a service as described above, it is a charitable corporation under New York State law.

Karen J. Golding-Kushner

The Golding-Kushner Speech Center

The Virtual Center for Velo-Cardio-Facial Syndrome, Inc.

East Brunswick, NJ

Disclosure: Karen J. Golding-Kushner Associate Coordinator for ASHA Special Interest Group 18, Telepractice. She is affiliated with the Virtual Center for Velo-Cardio-Facial Syndrome, Inc., which is described in this article in order to discuss the application of telepractice internationally. This center is a nonprofit corporation, and although it is a service as described above, it is a charitable corporation under New York State law.

Access to the Internet and modern telecommunications around the world has increased substantially to the point where, in many parts of the world, it is easier to get online or make an international telephone call than to gain access to a speech-language pathologist. There are many parts of the world where speech-language professionals are not available at all, but substantial segments of the population do have access to the Internet. Overall, worldwide access to the Internet is approximately 30% of the population, ranging from nearly 80% in North America to approximately 11% in Africa (Internet World Stats, 2011). However, even in the locations where Internet access is not as widely available as in the United States, it is still more accessible than face-to-face speechlanguage pathology services. The limited access to services has been recognized as a reason for providing them by using telepractice paradigms. Many communication disorders lend themselves to assessment and treatment using video and/or audio technology. This article reports on models for providing care to people at a distance, including internationally, and presents a new model for allowing clinicians to reach people all over the world. The authors present possible obstacles as well as some misconceptions about limitations for the purpose of finding ways to allow our clinical skills to be applied to new technologies that are gaining wider acceptance.

The aphorism "it's a small world" predates the development of the Internet and advanced telecommunications, but over the past decade, there is no doubt that the world is shrinking in many respects. International travel is increasing, telephone calls are a fraction of the cost they once were, and the Internet allows instant communication at essentially no additional cost to people who are connected to the worldwide web. Today, the biggest obstacle to speaking directly to someone who is thousands of miles away is synchronizing time zones.

Access to computers and the web, while not available to everyone, is growing everywhere, and the devices that can access the Internet are becoming more portable and less

dependent on location. It is estimated that in 2011, approximately 30% of people in the world utilized access to the Internet (Internet World Stats, 2011). This includes a rate of approximately 78% in North America, 60% in Oceania/Australia, 58% in Europe, and 36% in Latin America. Internet access in the most populace continent, Asia, was used by 23% of its population, while Africa had the most limited connectivity at about 11%. In terms of population, however, this means that there are currently at least two billion people in the world who have access to the Internet to some degree. This conduit to all of the information that exists on the Internet presents an opportunity for people to learn, converse, seek advice, offer their own opinions, and ask questions in addition to shopping, banking, and other business. It is known that at least 80% of people who use the Internet search out information about health care (Fox, 2005). Information of this type can come from many sources that can include hospital-based websites, health information websites, blogs, support groups, and, most recently, companies that provide medical advice or treatment for a fee. Information—more specifically, consultations providing information that may be difficult to obtain in a busy office where time is typically short—can be given in a private atmosphere and is not dependent on geography or proximity to the person giving the information. Because geography is not a factor, this type of consultation is ideally suited to international use.

Speech-language pathology as a health-care specialty is not as uniformly available as medical care. Physicians and nurses exist in essentially all nations; this is not true for speechlanguage pathologists. There are some nations where the specialty does not exist and others where the population is so underserved that only a very small number of people would have access to practitioners. Even in nations where speech-language pathologists are available in larger numbers, the access to clinicians is not as universally available as in the United States. In many nations, if not most, speech and language services are not available through the public school systems. It is also true that in many nations that have government-run educational systems, many people prefer to send their children to private schools because of the perception that they are superior to public schools. Speech-language pathology services are not available in private schools outside of the United States. Diagnostic and therapy services in many nations are more likely to be found in hospitals, clinics, or private practices, and therefore may not be accessible for many people because of expense or logistics. Even in areas where speech-language pathology services are available, expertise in treating some disorders may be lacking, a problem that is also leading to the growth of telespeech services in the United States.

The limited access to health-care services has been recognized as a solid reason for provision of some services by telepractice by many hospitals, and both Medicare and private insurers are beginning to reimburse practitioners for its use in the United States. More than a dozen states mandate payment for telepractice (Macios, 2010). At face value, it would seem obvious that speech-language pathology practices would be ideally suited to telepractice. Speech-language pathologists are less dependent on physical examinations than physicians, many of their decisions and recommendations are based on listening to the speech production of their patients, and many standardized tests can be easily adapted to use over video or telecommunication systems. Although physical examinations are important, particularly oral examinations, a local clinician can perform these examinations. Examinations by local clinicians can be supplemented by intra-oral photographs that can be requested and sent by email or file transfer protocol.

International use can be complicated by differences in language between the speech-language pathologist and the recipient of the service, but these issues are not different from language differences in a multicultural environment and can be overcome by multilingual clinicians, interpreters, or patients who speak English fluently. However, for certain disorders such as voice, fluency, or resonance impairments, language may not be an issue in terms of assessment. Articulation and language disorders may present a bigger challenge, but a

substantial amount of information can be obtained through history by using an interpreter, especially if that interpreter has some background or experience with speech disorders.

The purpose of this article is to discuss our experience with the use of telepractice in following a group of international patients with a specific genetic syndrome that requires specialized knowledge not readily available in many locations. The application of this technology proved to be very effective in providing vital information to the patients, assuring the clinicians that care provided to them was being effective, and reducing the expense to patients who would otherwise have to spend thousands of dollars in travel for appointments. We also will discuss issues related to potential obstacles and ethical issues.

Patient Population

In 1978, Shprintzen and colleagues described a genetic multiple anomaly syndrome inherited as an autosomal dominant disorder in a cohort of twelve patients, which we labeled velo-cardio-facial syndrome (VCFS, MIM#192430). Between 1978 and 1992, a research team was assembled to study this disorder, resulting in the publication of many articles covering speech, language, and development (Golding-Kushner, Weller, & Shprintzen, 1985); congenital heart disease (Young, Shprintzen, & Goldberg, 1980); craniofacial anatomy and physiology (Arvystas & Shprintzen, 1984; Chegar, Tatum, Marrinan, & Shprintzen, 2006; Golding-Kushner, 1991; Shprintzen, 1982; Williams, Shprintzen, & Rakoff, 1987; Zim et al., 2003); cognition, brain, and behavioral disorders (Antshel, Fremont, Higgins, Shprintzen, & Kates, 2006; Golding-Kushner et al., 1985; Mitnick, Bello, & Shprintzen, 1994; Shprintzen, Goldberg, Golding-Kushner, & Marion, 1992); a variety of vascular, ophthalmic, and structural anomalies (Mansour, Wang, Goldberg, & Shprintzen, 1987); and genetics (Scambler et al., 1992; Shprintzen, Goldberg, Young, & Wolford, 1981; Williams, Shprintzen, & Goldberg, 1985). In the early years of recognition of the syndrome, nearly all of the cases seen in our program were newly diagnosed after they were referred to us because of clinical features of the syndrome, such as hypernasal speech, cleft palate (including submucous clefts), severe articulation impairment and language delay, developmental delay, and feeding problems. Then, in the 1970s and 1980s, all diagnoses were clinical (molecular genetics tests were not yet developed) and few, if any, cases came to us with the diagnosis established elsewhere. This all changed in 1992.

In 1992, there was a dramatic shift in the recognition of VCFS and its diagnosis. We reported a high frequency of mental illness as a feature of the syndrome (Shprintzen et al., 1992) and, shortly after, the first papers were published documenting that the syndrome was caused by a deletion of DNA from the long arm of chromosome 22 at the 22q11.2 locus. Because there was a strong interest supported by the Human Genome Project to isolate genetic causes for mental illness, a large number of researchers and clinicians became interested in VCFS and within the next few years, hundreds of publications followed. At the same time, The Velo-Cardio-Facial Syndrome Educational Foundation, Inc., a group of professionals, parents of children with VCFS, and adults with VCFS, became active in distributing information to the public and academic programs. Within a short period of time, large research programs formed internationally, spurred in part by the Internet as well as available grant funds from a number of sources. A molecular genetics test (Fluorescence In Situ Hybridization or FISH) was developed, followed more recently by comparative genomic hybridization (CGH) microarray analysis, that could be ordered almost anywhere in the United States and in many countries around the world. Soon, children with congenital heart disease, cleft palate, and other anomalies were being screened for the deletion from chromosome 22. Within a few short years, thousands of children were identified and the need for clinical care to become available became obvious. Unfortunately, the number of clinicians with specific knowledge of VCFS and some of the syndrome-specific treatments that needed to be applied lagged behind the research community's efforts to delineate the genomic contributions to the syndrome and its many clinical features. VCFS has perhaps the most expansive phenotypic spectrum of any multiple

anomaly syndrome, with nearly 200 clinical features described to date (Shprintzen & Golding-Kushner, 2008). Therefore, many people affected by the VCFS, especially in more isolated communities far from academic medical centers, were at a disadvantage in terms of recognition of the special needs associated with the syndrome and its treatment. Our program received hundreds of contacts every month, literally from all over the world, seeking advice and inquiring if they could come to us for treatment, often from thousands of miles away in Europe, Asia, Africa, and South America. These visits were very expensive and could not be repeated for most people. Many people could not come because of the lack of appropriate insurance or funds for multiple airfares, lodging, and food. Therefore, we formed a "distance care" program.

Distance Care

Our first model for distance care was dependent on patients making one visit for an initial consultation in order to allow an interdisciplinary assessment because of the complexity of the syndrome. Once that initial evaluation was completed, it was possible to follow patients by one of three methods: e-mail, telephone, or video, either by video calls or recorded videos sent to us over the Internet or on a disc via the postal service. Prior to the patient's first visit, detailed medical records were thoroughly reviewed by multiple professionals in order to triage the patient on arrival at our center. Over a period of years, we found that this extremely careful review of past medical history and long interviews with patients and their families prior to their arrival, combined with our team's base of knowledge and expertise with VCFS, often resulted in a substantial amount of evidence for decision-making, especially when supplemented by videos of speech, instrumental examinations, and the review of the reports of physical examinations by other professionals. We found that analysis of problems, especially those associated with speech production, could be highly accurate based on information obtained from a distance by combining a store-and-forward approach with real-time (synchronous) videoconferencing.

If the primary reason for referral of the patient was concern over hypernasal speech and its treatment, we would request either a live Internet video session or a video of a standardized speech sample (in the patient's native language) plus a sample of spontaneous speech that could be sent to us on a disc or tape, by e-mail or file transfer for large files, or posted on a website such as YouTube® with settings adjusted for private viewing. We found this to be an effective way to screen cases who might have been inappropriately diagnosed with velopharyngeal insufficiency but clearly did not have it. Screenings using real-time video contact allowed us to manipulate the patient's speech sample, such as having them occlude their nostrils to determine if there was evidence of resonance shift during normally non-nasal speech or to detect the presence of nasal fricative substitutions that would have been mistaken for velopharyngeal insufficiency by clinicians who did not have extensive experience with these disorders. In such cases, we would offer to communicate with local professionals to inform them of therapy techniques that would prove effective, thereby saving patients time and money by avoiding a trip to our center, which could involve enormous expense to the family. We would also provide resources to the family of the patient that would provide them with information relevant to treatment. A follow-up video session would be scheduled appropriate to an expected timeframe for progress in order to determine the efficacy of both the recommendations and the local clinicians. If the local clinicians were willing, we would ask for a recorded or contemporaneous video session of therapy so we could either interact with the local clinician or critique the session and offer both suggestions and reinforcement. Our experience was that the local clinicians who were willing to enter the process of having their therapeutic sessions observed were typically willing to make modifications, and they often saw this process as educational for themselves. Therefore, remote video review of therapy served two purposes: establishing good treatment for the patient and educating clinicians who were unaware of effective treatments for rare conditions.

Efficacy of Our Distance Care Model

Because our distance care model still required an initial evaluation at our center, the majority of our patients were people who lived within driving distance and whose insurance would cover their evaluation, or people who could afford the travel and fees associated with the comprehensive evaluation. Expenses for travel, evaluation, and, on occasion, treatment could run into the thousands or tens of thousands of dollars. Therefore, our patient population tended toward people of more substantial means, preventing many people from receiving care and essentially eliminating patients receiving Medicaid or other public-supported insurance policies from visiting us unless they lived in New York State.

Another problem was the "one moment in time" factor. Although our comprehensive team evaluations were often two or three days in length, the contact with the patient may not have always been an accurate reflection of the scope of the individual's true clinical picture. This was especially true for the behavioral components of the disorder. Children with VCFS tend to do poorly in unfamiliar surroundings and may respond poorly to examiner's requests, thereby altering the assessments. It is therefore possible that an expensive physical visit to a facility may not yield accurate results rendering the recommendations of limited value.

A major factor in the success of the distance care program was that it was not fully dependent on physical contact with the patient. However, it was not only the telepractice follow-ups that were key to this process. We learned from doing audits on our efficacy that our success was actually based more on information we received and analyzed before we saw the patient. Our practice was to pre-assess patients in a two-step process before accepting them as patients. The first step was to fill out a form that asked pointed questions, more than a simple medical history. The form was based on our special knowledge of VCFS and included questions about possible problems, possible treatments and their outcomes, and developmental and behavioral aspects of the syndrome that have been observed frequently in children with VCFS. Based on the review of that form by our nurse practitioner Clinical Coordinator, we would then communicate to the patient specific medical records that we needed to review and ask them to forward them to us by post, fax, e-mail, or file transfer protocol. If there were concerns about speech, we would ask for a video speech sample (specified in terms of the type of speech sample needed) and any instrumental studies that might have been done, such as fluoroscopic and endoscopic examinations. If there were a history of radiographs (including computed tomography [CT] scans, magnetic resonance [MR] scans, or ultrasound examinations), we would ask for copies of the actual examinations for our review—something that is far easier today than in the past with the use of digital storage of such procedures. We found that this comprehensive review prior to hands-on contact with the patient almost always yielded conclusions about the patient and his or her management that were confirmed after our own examinations. Because so many of our patients had been evaluated thoroughly by their local physicians, the missing element in their care was not the comprehensiveness of the evaluation, but rather the special knowledge of a rare condition that was necessary to reaching the correct conclusions.

A New Model

In order to make special expertise available to a wider range of people anywhere in the world—whomever may request it—and knowing that the process of evaluation could often be successful in the absence of physical contact with the patient, the team developed a new model that is based on the use of technology that would be able to reach any individuals who have access to the Internet, e-mail, or a telephone. In principle, we developed a *Virtual Center* that will allow the collaboration of an interdisciplinary team selected not because of their location, but because of their expertise. We assembled a team of professionals, all of whom have exceptional levels of expertise with VCFS over decades of practice in multiple disciplines ranging from speech-language pathology to clinical and molecular genetics. The center is a charitable corporation that will not charge a fee to its users. People interested in learning about

options for managing VCFS would access our experts through our website, www.vcfscenter.com. The process follows the steps outlined below:

- Filling out Internet-based forms: The website provides a general description of the Virtual Center, its mission statement, biography of the staff, and general information about VCFS. The person making contact is asked to register in order to determine if he/she would benefit from a consultation. Once registered, he/she would be asked to fill out Internet-based forms including:
 - o An acknowledgment form indicating that the consultants provide information for the purposes of educating clinicians local to the user, enabling them to be familiar with all appropriate diagnostic procedures and treatment options. Our consultants include available outcome data and publications documenting outcomes. The registrant is told clearly that the consultants with the Virtual Center are not establishing a provider-patient relationship and are not taking responsibility for direct care with the registrant, but rather providing educational information that the registrant might find useful if applicable to his/her situation.
 - A history form, as described above. The form could be downloaded for future transmission to the Virtual Center or filled out and uploaded online. This form is treated as scenarios or set of circumstances that would shape the type of information developed by the consultants.

These forms are reviewed by the Information Coordinator, a nurse practitioner with 15 years of clinical and research experience exclusively with VCFS. In a previous setting, she functioned as a Clinical and Research Coordinator, managing hundreds of patients with VCFS by reviewing records, collecting outcome data, and triaging them to other professionals within the institution. The Information Coordinator determines if the user is a good candidate for the service provided by the Virtual Center, communicates with the consultants as necessary, and then returns the contact.

The Second Stage: Contacting the Registrant

This stage of the process involves a return contact from the Information Coordinator by the preferred mode of communication (e-mail, telephone, fax, or postal service). During that return contact, the Information Coordinator would:

- Review the history form and question the user about anything that is unclear or needs elaboration. If reports of radiographic procedures are found, the actual procedures (CT scans, MR scans, radiographs, ultrasounds) are requested for review. The user is given an opportunity to ask questions.
- Provide a description of what the Virtual Center can do and how it works. There are two major components:
 - Consultations: The purpose of the consultation is to give information and the benefit of expertise to local practitioners. It will be the responsibility of the user to determine if their local practitioners are willing to interact directly or indirectly with the experts. Ideally, a videoconference call will be scheduled with the experts, local practitioners, and user to discuss the issues surrounding the specific problems that concern the user. As acknowledged by the registrant, the information cannot be construed as specific recommendations or prescriptions for a particular person who would be supervised by the consultants, because this would imply a clinician-patient relationship, which this is not. Information from the Virtual Center's consultants may help the client and the local practitioners who are responsible for the care of a particular person diagnose and treat their patients based on the experience of the experts and outcome studies that have been published. In a way, the process would be similar to that of a visiting expert to a hospital in another state or country who is asked to

- render opinions on the management of either specific patients or groups of patients (so-called *visiting firemen*). This process will not only give users the advantage of getting state-of-the-art information about their specific concerns, but it will also be a grassroots method for educating local practitioners whose experience might be more limited specific to VCFS.
- o A request for outcomes: The expert consultants would like to assess the efficacy of this model and determine if their information is useful to the users and results in improved outcomes. The user would therefore be asked if it would be reasonable for the Virtual Center to call them periodically to ask if their consultations have proven to be useful.

The Third Stage: Conference Video or Conference Call

Once the user has been accepted into the program, the Information Coordinator will begin the process of scheduling a video or telephone conference call that would ideally involve the user, the Virtual Center's experts, and local clinicians. If the local clinicians are not available to join the conference or it is too difficult to schedule because of time zone differences, the discussion between the experts and the user is recorded (either video or audio) and provided to the user for transmission to the local clinicians.

Practical Problems in Implementation

The use of telepractice is complicated because of issues that are vexing current practitioners in the United States who are trying to serve local populations efficiently and within the bounds of current law and ethical guidelines.

Legality, Regulations, and Licensure

Issues that impact practitioners in the United States in relation to legality (primarily in relation to the Health Insurance Portability and Accountability Act [HIPAA]) and licensure present a major hurdle to the implementation of the Internet and technology for the delivery of services. HIPAA is an excellent example of government regulation that has had some unintended consequences that can negatively impact the use of technology designed to advance patient care. Because HIPAA is rife with penalties, including substantial fines for violations, purposeful or not, clinicians are extremely cautious about using the Internet as a health-related service. However, the restrictions imposed by HIPAA for U.S. patients do not apply for people seeking this type of service from outside of the United States, therefore relieving clinicians of the concerns related to violating those specific laws. Moreover, HIPAA does not apply to organizations that are not health-care providers. For example, The Virtual Center for Velo-Cardio-Facial Syndrome is not a health-care provider. Hospitals, clinics, and other institutional practitioners are subject to HIPAA laws.

When people seeking care or information are outside of the United States and communicate over the Internet with U.S. health-care providers, the exchange of information and material provided by the patient are not subject to HIPAA, which applies only to people on U.S. soil (Commins, 2011). Although U.S. health-care providers would be obligated to follow the laws of the country where the patient was located (Thompson et al., 2011), HIPAA as a specific law is irrelevant. However, it has been suggested by some medical ethicists that patients outside of the United States should be treated exactly the same as patients who are covered by HIPAA (Commins, 2011). A question would be if treating patients abroad in the same way as American patients protected by HIPAA is to their advantage or not. It might be perceived that by following all of HIPAA's regulations for patients in, for example, Italy, we may not be doing them any favors. Therefore, it is recommended that consent and release forms be used for all patients, including foreign users, and that consultations not proceed without these signed documents. If English is not the primary language of the user and the user's family, then it would be important to have the same document translated into the native language of the

person signing. The laws of the country where the patient lives should be understood in terms of age of consent or assent.

Although patients' information existing on the Internet is a source of concern to clinicians, fearing the consequences of HIPAA violations and possible law suits, it should be noted that public access to medical information about specific individuals is everywhere online. As discussed by Geyser (2009), many people willingly sign releases for the posting of some or all of their health-care information and status in order to share good/bad news, support a health-care provider or institution, or in an effort to help people obtain similar results they have achieved based on specific treatments. Some of these public disclosures are contained within advertisements, others are on the websites of support groups or charitable foundations, and still others on social media networks such as Facebook® and Twitter®. The public sharing of this information is of no concern in terms of HIPAA or legal action because the people posting the information had all necessary release forms signed or, if on social networks, the information was posted voluntarily by the people themselves and was not intended for a particular clinician or institution. Therefore, although ethicists may believe that patients from outside of the United States should have their information treated in exactly the same manner as U.S. patients, the use of appropriate release forms will protect the care provider.

Another example of regulation is the issue of portability of licenses across state lines. This issue may be irrelevant in countries outside of the United States if there are no specific license requirements for speech-language pathologists. It is important for clinicians to research local laws in other nations to determine what type of legal protection they would need to have to service clients in that nation, including acknowledgment or disclaimer forms covering the service provided.

Liability and Logistics

The fear of litigation over information and consultation provided over the Internet to patients outside of the United States is also highly dependent on the nation where the information is received and their legal systems with reference to malpractice lawsuits. One mechanism for avoiding this entanglement is not to provide treatment recommendations directly to the patient or the patient's family and to reiterate that the information provided is not to be construed as direct care. We have taken the approach of discussing the patient's situation within the context of what we know about the patient and the diagnosis, outcome studies, or personal experience with treatments, and transmit that information to the local health-care providers. Because we will not be seeing these patients in any manner other than a remote contact by electronic means, we are acting in much the same way a lecturer or visiting professor does when asked to visit a health-care facility overseas. Both authors on this paper have visited many programs in Europe, the Middle East, Central and South America, Asia, and Australia. During these visits, we are asked for our expertise so that local clinicians can learn and possibly implement procedures we know to be effective. That same information can be provided in many ways, including within the context of discussing a single patient's condition and what expected outcomes might be for specific treatments. This spreading of information is a traditional practice in health care and a frequent educational practice around the world. The role of "experts" can be applied with a narrow focus or a broad brush, but the final recommendation in terms of a specific patient is made by the local practitioner. Because the treatment is in the hands of the local practitioner, any liability for malpractice resides with him or her.

It is obvious that the model of communicating ideas and thoughts about treatment to a local professional also has the advantage of adding an education process to patient care, as well as developing solid grassroots contacts with people in other countries that can have some very attractive side effects: the establishment of friendship in a completely apolitical atmosphere, bidirectional learning with colleagues in other countries, and improving care for rare disorders worldwide.

Logistical problems associated with the use of telepractice, especially Internet use, include time zone differences; language differences (discussed above); and Internet and broadband availability, speed, cost, and, in some societies, privacy and security of service. Nothing can be done about time zone differences other than to find an appropriate overlap of "business hours" at both ends of the connection. Europe is typically a five, six, or seven hours' difference from the east coast of the United States (eight to ten hours from the west coast); early morning in the United States is usually late afternoon or evening in Europe, which does allow for reasonably convenient times at both ends. The east coast of Australia is 14 hours ahead of the east coast of the United States, allowing for some overlap in the late afternoon or early evening. The most problematic locations would be those on the exact opposite side of the world, such as Shanghai and Singapore, which are 12 hours apart from the east coast of the United States. Some degree of flexibility is therefore necessary in dealing with patients located halfway or nearly halfway around the world.

Internet availability and its ability to carry high-speech connections can be an issue in some locales. Broadband Internet capabilities, although widely available, are not universally available. This may cause problems with video streams. It is reasonable to ask potential contacts the speed of their Internet service as well as the cost. In some countries, people pay high prices for service and often pay by the minute or by amount of data transmitted. Video recordings or streaming video may be prohibitively expensive for most people in some places. In some cases, telephone contact may be much less expensive than Internet access. In order to ease the way for people who may not be particularly Internet savvy, it is an excellent policy to have information on websites that informs users of the requirements for connecting to a particular service in an optimal manner, such as what options there are for video connections. For example, FaceTime is only available on Mac computers, while other video programs such as Skype or ooVoo can be accessed on both platforms. If dial-up Internet connection is the only option for people, then video connections are not possible, and this information should be explained.

The issue of security and privacy can be a problem in closed societies or places where the government closely watches its citizens, such as Iran, Cuba, and North Korea. People at both ends of the conversation for these kinds of contacts should do some homework to determine if the risk to either party is high.

Summary and Conclusions

The Internet and worldwide web and other electronic communication tools have altered connections between people irrevocably. For little or no cost, people from the United States can communicate with people on any other continent. Because the Internet has proven to be an often-used medium for the consumption of health-care information and, in some cases, diagnosis and treatment, its international application is not surprising. The ability to reach billions of people and to communicate with people whose health-care practices may vary widely from our own adds many opportunities for all involved. With solid preparation and due diligence, we believe that the benefit is a foregone conclusion.

References

Antshel, K., Fremont, W., Higgins, A. M., Shprintzen, R. J., & Kates, W. R. (2006). ADHD, major depressive disorder, and simple phobias are prevalent psychiatric conditions in youth with velocardiofacial syndrome (VCFS). *Journal of the American Academy of Child and Adolescent Psychiatry*, 45, 596–603.

Arvystas, M., & Shprintzen, R. J. (1984). Craniofacial morphology in the velo-cardio-facial syndrome. *Journal of Craniofacial Genetics and Developmental Biology*, 4, 39–45.

Chegar, B. E., Tatum, S. A., Marrinan, E., & Shprintzen, R. J. (2006). Upper airway asymmetry in velocardio-facial syndrome. *International Journal of Pediatric Otorhinolaryngology, 70,* 1375–1381.

Commins, J. (2011, February 22). Patient privacy rights extend beyond U.S. borders, ethicists say. *HealthLeaders Media*. Retrieved May 25, 2012, from www.healthleadersmedia.com/print/HR-262859/Patient-Privacy-Rights-Extend-Beyond-US-Borders-Ethicists-Say

Fox, S. (2005, April 14). *Dr. Google's office never closes*. Pew Internet. Retrieved May 25, 2012, from www.pewinternet.org/Presentations/2005/Dr-Googles-Office-Never-Closes.aspx

Geyser B. (2009, October 19). Social media and HIPAA: What you need to know. *CareNetworks*. Retrieved May 25, 2012, from www.carenetworks.com/social-media-and-hipaa-what-you-need-to-know

Golding-Kushner, K. J. (1991). *Craniofacial morphology and velopharyngeal physiology in four syndromes of clefting* (Unpublished doctoral dissertation). The Graduate School and University Center, City University of New York, New York City, NY.

Golding-Kushner, K. J., Weller, G., & Shprintzen, R. J. (1985). Velo-cardio-facial syndrome: Language and psychological profiles. *Journal of Craniofacial Genetics and Developmental Biology*, 5, 259–266.

Internet World Stats. (2011). *Internet world stats: Usage and population statistics*. Retrieved May 25, 2012, from www.internetworldstats.com

Macios, A. (2010, July 15). Payment for telemedicine gaining momentum. *Medscape Medical News*. Retrieved May 25, 2012, from www.medscape.com/viewarticle/725115

Mansour, A., Wang, F., Goldberg, R., & Shprintzen, R. J. (1987). Ocular findings in the velo-cardio-facial syndrome. *Journal of Pediatric Ophthalmology*, 24, 263–266.

Mitnick, R. J., Bello, J. A., & Shprintzen, R. J. (1994). Brain anomalies in velo-cardio-facial syndrome. *American Journal of Medical Genetics*, *54*, 100–106.

Scambler, P. J., Kelly, D., Lindsay, E., Williamson, R., Goldberg, R., Shprintzen, R. J., . . . Burn, J. (1992). Velo-cardio-facial syndrome associated with chromosome 22 deletions encompassing the DiGeorge locus. *Lancet*, 339, 1138–1139.

Shprintzen, R. J. (1982). Palatal and pharyngeal anomalies in craniofacial syndromes. *Birth Defects Original Article Series*, 18(1), 53–78.

Shprintzen, R. J., Goldberg, R., Golding-Kushner, K. J., & Marion, R. (1992). Late-onset psychosis in the velo-cardio-facial syndrome. *American Journal of Medical Genetics*, *42*, 141–142.

Shprintzen, R. J., Goldberg, R. B., Lewin, M. L., Sidoti, E. J., Berkman, M. D., Argamaso, R. V., . . . Young, D. (1978). A new syndrome involving cleft palate, cardiac anomalies, typical facies, and learning disabilities: Velo-cardio-facial syndrome. *Cleft Palate Journal*, 15, 56–62.

Shprintzen, R. J., Goldberg, R., Young, D., & Wolford, L. (1981). The velo-cardio-facial syndrome: A clinical and genetic analysis. *Pediatrics*, 67, 167–172.

Shprintzen, R. J., & Golding-Kushner, K. J. (2008). *Velo-cardio-facial syndrome, Volume 1*. San Diego, CA: Plural.

Thompson, L. A., Black, E., Duff, W. P., Black, N. P., Saliba, H., & Dawson, K. (2011). Protected health information on social networking sites: Ethical and legal considerations. *Journal of Medical Internet Research*, 13(1), e8. doi:10.2196/jmir.1590

Williams, M. A., Shprintzen, R. J., & Goldberg, R. B. (1985). Male-to-male transmission of the velo-cardio-facial syndrome: A case report and review of 60 cases. *Journal of Craniofacial Genetics and Developmental Biology*, 5, 175-180.

Williams, M. L., Shprintzen, R. J., & Rakoff, S. J. (1987). Adenoid hypoplasia in the velo-cardio-facial syndrome. *Journal of Craniofacial Genetics and Developmental Biology*, 7, 23–26.

Young, D., Shprintzen, R. J., & Goldberg, R. (1980). Cardiac malformations in the velo-cardio-facial syndrome. *American Journal of Cardiology*, 46, 43–48.

Zim, S., Schelper, R., Kellman, R., Tatum, S., Ploutz-Snyder, R., & Shprintzen, R. J. (2003). Thickness and histologic and histochemical properties of the superior pharyngeal constrictor muscle in velocardiofacial syndrome. *Archives of Facial Plastic Surgery*, *5*, 503–507.