### **Diabetes Legal Advocacy Comes of Age**

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#### Abstract

This article updates the legal advocacy efforts of the American Diabetes Association since 1999. These efforts include a variety of strategies and tactics to improve the lives of people discriminated against on the basis of their diabetes. The Association's efforts are particularly focused on employment and school issues, but they also include access to medical care for people in correctional institutions and at places of public accommodation. Using an overall strategy

of educating, negotiating, litigating, and legislating, the Association has achieved significant results with farreaching effects. This innovative effort is unique among voluntary health organizations. The Association has institutionalized its legal advocacy efforts with its strategic plan, budget allocations, volunteer networks, and staff support. The legal advocacy efforts of the Association bring significant and meaningful results to people with diabetes.

During the winter of 1999, an original article in *Diabetes Spectrum* outlined the history of legal advocacy for the American Diabetes Association from 1990 through 1999. Legal advocacy refers to the Association's efforts to end discrimination against people with diabetes. This article takes legal advocacy from 1999 to the present, updating the Association's achievements, efforts, and strategies.

Since 1999, the Association's legal advocacy efforts have been expanded and strengthened and now are significantly more effective in different venues on a wide variety of issues. The theme of the previous article was the dawn and development of legal advocacy for diabetes. The theme of this article is the growth and implementation of legal advocacy to improve the lives of all those affected by diabetes.

The implementation of legal advocacy for diabetes focuses on an overall process that is incremental, inexorable, yet flexible. The Association pursues a four-step process to *educate* about diabetes, to *negotiate* resolutions of problems, to *litigate* if necessary to protect rights and remedies, and, where current legal protections are not adequate, to *legislate* new laws, rules, and standards for people with diabetes. This process produces lasting, significant results.

## STRATEGIES FOR DIABETES LEGAL ADVOCACY

The Association uses various strategies to protect the legal rights and remedies of people affected by diabetes.

#### **Education Efforts**

The Association realizes that much of the discrimination against people with diabetes is based on ignorance of diabetes and current methods of diabetes management. Decision makers, from employers to school personnel to judges, do not understand the disease of diabetes, the requirements of diabetes management, or the capabilities of people with diabetes. People with diabetes do not understand their legal rights. The Association devotes a great deal of its legal advocacy efforts to creating and providing the tools people with diabetes need to educate both themselves and those who discriminate against them.

## Creating and maintaining position statements

The Association establishes, reviews, and maintains the most authoritative and widely followed clinical practice recommendations, guidelines, and standards for the treatment of diabetes.<sup>2</sup> It publishes the most influential professional journals concerning the treatment of diabetes and developments in diabetes research.<sup>3</sup>

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The Association addresses major issues involving the protection of the legal rights and remedies of people affected by diabetes through its position statements. There are now three position statements that are the foundation for the Association's legal advocacy efforts. These statements are the product of a vigorous peer review process to guarantee that they reflect the most current medical and scientific consensus and expertise.

Employment. In the employment arena, the Association's position statement on hypoglycemia and employment/licensure," which had its origins in the mid-1980s, is a clear statement of the role that diabetes should play in the individual assessment of the ability of people with diabetes for any job.

Education. In late 1998, the Association developed a position statement on diabetes care in the school and day care setting<sup>5</sup> in response to a growing demand from both the families of students and school personnel for appropriate and workable diabetes management guidelines for students while in school. This position statement provides a comprehensive and pragmatic protocol to address the health care needs of students.

Correctional institutions. In 2003, the Association completely revised its position statement on diabetes management in correctional institutions<sup>6</sup> in response to shocking revelations concerning the lack of effective diabetes management for people in custody, both before and after criminal conviction, in a variety of different institutions from police holding facilities to state penitentiaries. The goal of the revision was to adapt the Association's Standards of Care clinical practice guidelines to the corrections environment. A task force composed of the Association's experts in endocrinology and diabetes management and experts in correctional medicine from the National Commission on Correctional Health Care was charged with writing an updated, expanded position state-

This position statement caused an immediate effect on the quality of diabetes care for people being held in custody or who were incarcerated, e.g., in Alabama, it became the basis of the settlement of a class action law-

suit involving prison conditions brought by the Southern Poverty Law Center.<sup>7</sup> As with the position statement for students, this position statement encompasses the most current medical knowledge, science, and technology to create a workable protocol for effective management of diabetes in the restricted environment of a correctional institution.

With these position statements as the foundation, the Association uses an array of methods to educate decision makers, people with diabetes, and advocates for people with diabetes.

#### Educating decision makers

The Association publishes books, magazines, and brochures that explain every aspect of diabetes management as well as specific diabetes legal advocacy efforts.

In 2000, the Association approached the National Institutes of Health (NIH) and the Centers for Disease Control and Prevention (CDC) to request the creation of an authoritative document that would represent a consensus on how to keep kids with diabetes safe in school. This effort led the National Diabetes Education Program (NDEP), a joint effort of the CDC, NIH, and > 200 partner organizations, to form a coalition of organizations with expertise in diabetes and education to create Helping the Student With Diabetes Succeed: A Guide for School Personnel.8

The use of this comprehensive guide for managing diabetes in a school environment is supported by an impressive list of federal agencies and education and diabetes organizations (Table 1). With the imprimatur of these organizations, the NDEP guide is now the authoritative voice on what is needed for students with diabetes to be medically safe at school and have equal access to educational opportunities.

One of the basic tenets of the Association's position on diabetes school care is that adequate diabetes care requires the presence at all times of an adult who can provide routine care (e.g., blood glucose monitoring and insulin injection) for students who are not able to self-manage these tasks and who can provide emergency care (e.g., glucagon administration) for all students with diabetes. The Association developed

a series of modules that are available to certified diabetes educators, school nurses, and others to provide training to school staff. These training modules demonstrate the Association's commitment not simply to tell others what to do, but rather to form partnerships with them to create and implement a safe and discrimination-free school environment.

In the employment area, the Association's educational materials range from a brochure for employers developed in conjunction with Cornell University<sup>10</sup> to guidelines for employing people with diabetes. Efforts in the areas of firefighting and law enforcement are of particular interest.

In 2003, the National Fire Protection Association (NFPA) adopted a blanket ban on employment as a firefighter for anyone who took

#### Table 1. Agencies and Organizations Supporting the Use of the NDEP Guide<sup>7</sup>

- American Academy of Pediatrics
- American Association for Health Education
- American Association of Diabetes Educators
- American Diabetes Association
- American Dietetic Association
- American Medical Association
- Barbara Davis Center for Childhood Diabetes
- Centers for Disease Control and Prevention
- Indian Health Service
- Juvenile Diabetes Research Foundation International
- Lawson Wilkins Pediatric Endocrine Society
- National Association of Elementary School Principals
- National Association of School Nurses
- National Association of Secondary School Principals
- National Association of State Boards of Education
- National Diabetes Education Program
- National Education Association Health Information Network
- National Institute of Diabetes and Digestive and Kidney Diseases
- National Institutes of Health
- U.S. Department of Education

insulin and limited opportunities for all firefighters or potential firefighters with diabetes.11 NFPA is an organization that develops standards on all aspects of firefighting, which many fire agencies then adopt as policy. After much effort, the Association, through its attorneys and medical experts, persuaded the NFPA to appoint a medical task force to review those guidelines and develop an individual assessment protocol that permits people with diabetes, including those who take insulin, to be employed as firefighters.<sup>12</sup> This protocol is currently working its way through the multistep internal NFPA approval process.

This was a tedious and difficult process that eventually bore fruit because of the great working relationship between the legal and medical sides of the Association's legal advocacy program. The lawyers provided the legal analysis and potential threat of litigation, while the endocrinologists provided the medical and scientific expertise in dealing with the use of insulin in a firefighting environment.

Law enforcement is another area in which people with diabetes have historically faced a great deal of discrimination, including blanket bans. The Association worked with the American College of Occupational and Environmental Medicine (ACOEM) to create guidelines for law enforcement agencies to effectively and legally evaluate the work capacity of individuals with diabetes for a variety of law enforcement jobs. As with the NFPA standards, the ACOEM proposal is currently working its way through an internal approval process and will be a useful guide to both employers and physicians who evaluate employees for law enforcement positions.

Educating people with diabetes

During the past 6 years, the Association went from receiving a small but constant stream of calls and letters requesting help in discrimination matters to receiving an average of > 300 inquiries each month. The reason for this increase is not because of an increase in discrimination, but rather because of a growing awareness of the Association's dedication to ending discrimination and the publicity surrounding its successes.

The Association developed a successful method of providing help for such inquiries. First, it created extensive written materials, particularly in the areas of employment and school or day care discrimination. These include original materials that discuss the impact of various laws on people with diabetes, as well as a compilation of materials from government enforcement agencies and organizations that specialize in the civil rights of people with disabilities. Individuals seeking help on a discrimination matter are directed to call the Association's general toll-free Call Center (800-DIABETES) to obtain a packet containing these written resources. The Association also makes available on its website an extensive collection of materials to help educate people with diabetes and their advocates about a variety of legal issues.<sup>13</sup> These materials are regularly updated and supplemented. With the availability of this powerful technology, legal advocacy materials are readily available to all interested parties.

Individuals who are being discriminated against because of diabetes can also speak to the Association's legal advocate or another staff member or volunteer attorney. The legal advocate is an Association staff attorney who provides information and resources specific to an individual's concerns, including ideas on how that person might use education and negotiation to try to resolve the discrimination problem and, when needed, the names of local attorneys who may be willing to provide help. An average of 65 people each month seek such individual assistance for a discrimination problem.

Finally, Association legal advocacy staff and key volunteers present seminars on discrimination issues in a variety of forums ranging from Association events to conferences of other organizations to community hospitals.

By talking to individuals affected by discrimination, the Association is able to provide direct assistance to those facing discrimination, many of whom are then able to self-advocate to resolve their problems. Also, it is through these contacts that the Association is able to identify areas in which discrimination is concentrated, as well as spot cases that could be precedent setting. Providing this individual assistance guides much of the Association's legal advocacy work.

Educating lawyers and advocates A key component of the Association's legal advocacy work is providing guidance to lawyers and other advocates. The Association publicizes its involvement in legal advocacy efforts through presentations to groups such as the National Employment Lawyers Association (NELA). Association staff and volunteer lawyers consult with government and private lawyers who contact the Association because they are involved in a diabetes discrimination case. The Association's goal is to reach these lawyers as early in the process as possible to provide advice on developing the medical record needed to build a winning case.

The Association maintains an extensive collection of background and litigation materials on its website. These materials include all of the Association's amicus curiae briefs (discussed more below), other key diabetes briefs, and many outlines, fact sheets, and articles on a variety of specific legal issues. In October 2005, the Association published Legal Rights of Students With Diabetes, a comprehensive treatise on the legal rights of students with diabetes. 15

In addition to written materials, the Association recently expanded its efforts to train advocates, starting with a train-the-trainer seminar for advanced school advocates in spring of 2005. Nearly 30 advocates from across the country learned how to provide individual assistance to parents facing discrimination problems at school and to facilitate school advocacy workshops in their communities. In October 2005, > 60 lawyers attended a 2-day seminar titled "Fighting for Fairness: Ending Discrimination Against Students and Workers With Diabetes." As with the school advocates, these lawyers committed to continuing efforts to combat discrimination by handling cases referred by the Association, providing legal research, and assisting in legislative campaigns.

## Building and Nurturing Cooperative Relationships

Since 1999, the cooperative relationships between the Association and other organizations grew dramatically. The purpose of such relationships

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is not only to marshal more resources to apply to a particular legal advocacy problem, but also to create legal leverage from a variety of different perspectives. These relationships sustain a legal advocacy effort that has breadth, depth, and power. Increasingly, these creative and vibrant relationships involve a two-way interaction: the Association provides medical and scientific expertise, while its partners reciprocate with their political and legal expertise.

This cooperative strategy continues to garner increasingly effective results in the employment, educational, and correctional institution environments. In employment matters, the Association works closely with the Equal Employ-ment Opportunity Commission (EEOC), the Department of Justice (DOJ), and NELA on a variety of different issues in courts across the country.

In the educational arena, the Association works with organizations and agencies such as the Disability Rights Education & Defense Fund (DREDF) and the U.S. Department of Education (DOE). The Association developed a large coalition of professional and constituent diabetes organizations to endorse the Safe at School campaign's statement of principles (discussed more below) (Table 2).

In the correctional institutions area, the Association developed relationships with the National Commission on Correctional Health Care to develop workable diabetes management protocols in a difficult and restrictive environment. The Association is

## Table 2. Organizations Endorsing the Safe at School Campaign's Statement of Principles

- American Academy of Pediatrics
- American Association of Clinical Endocrinologists
- American Association of Diabetes Educators
- American Dietetic Association
- Children With Diabetes
- Juvenile Diabetes Research Foundation International
- Lawson Wilkins Pediatric Endocrine Society
- Pediatric Endocrine Nursing Society

working with the Southern Poverty Law Center, the American Civil Liberties Union, and the Morgan Lewis law firm to determine the best strategies to implement these protocols nationwide through the newly created National Diabetes Prison Coalition.

## Creating and Revising Regulations and Statutes

Historically, the Association expended considerable effort to change the regulations of various state and federal governmental entities and to change laws that restrict full participation by people with diabetes.<sup>16</sup>

#### Commercial driver's licenses

The longest struggle to revise and improve agency regulations involves the battle to allow people with diabetes who take insulin to be eligible for a commercial driver's license (CDL). The CDL affects a wide variety of jobs from commercial truck drivers to bus drivers to utility workers. In addition, although not legally permissible, employers in a variety of fields look to the U.S. Department of Transportation (DOT) and its previous prohibition on driving by people who use insulin as justification for limiting the employment rights of people with diabetes.

In 1998, after years of lobbying efforts by the Association, Congress passed legislation requiring the DOT to reevaluate its blanket ban on commercial driving by people who use insulin. As a result, in September 2003, the Federal Motor Carrier Safety Administration announced a diabetes exemption program providing for individual assessment and containing a number of stringent provisions to ensure safety.<sup>17</sup>

The Association supported the protocol with the exception of a "catch-22" provision that required an applicant to have driven a commercial vehicle while using insulin for the 3 years before seeking an exemption. It was legally impossible to have a 3-year driving history in interstate commerce and almost impossible to have such a driving history solely in intrastate commerce. Accordingly, very few individuals were eligible to apply for a CDL.

Subsequent efforts succeeded in passing legislation in 2005 that elimi-

nated the 3-year rule.<sup>18</sup> This accomplishment has far-reaching effects in many different kinds of employment that involve driving.

Safe at School campaign

Beginning with its work in securing passage of the first state school diabetes care law in Virginia and the first comprehensive administrative settlement through the DOE Office of Civil Rights in 1999, the Association became increasingly involved in school discrimination issues. The goals of school advocacy efforts are to make sure children with diabetes are medically safe at school and to ensure that students with diabetes have equal educational opportunities.

To meet these needs, the Association determined that:

- all school staff who have responsibility for a student with diabetes
  must have a basic understanding
  about diabetes and must know who
  to contact in an emergency
- a small group of staff members in addition to any full- or part-time school nurse should be trained to provide routine and emergency care when a nurse is not present
- students who are able to self-manage should be allowed to do so in the school setting.<sup>19</sup>

In July 2004, the Association launched its Safe at School campaign to tie together its efforts to educate parents and school personnel, negotiate reasonable accommodations, support litigation either through state or federal agencies or in court, and, when needed, change laws and regulations. As in all successful legal advocacy efforts, this campaign relies on a combination of staff and volunteer efforts, including lawyers, health care professionals, and students with diabetes and their families. Diabetes school care laws covering all or part of diabetes school care needs now exist in 15 states, including California, Connecticut, Hawaii, Kentucky, Massachusetts, Montana, North Carolina, Oregon, South Carolina, Tennessee, Texas, Utah, Virginia, Washington, and Wisconsin.

The Association faces strong, organized opposition to its school efforts from several school employee groups. These groups argue that only a nurse can provide diabetes care; that, in the absence of a nurse, a parent must come

to school to provide routine care; and that the proper response to emergency situations is to call 911. In response, the Association formed the coalition of professional and constituent diabetes groups described above (Table 2) to further strengthen the medical and scientific foundation for the position set out in its position statement<sup>5</sup> and in the NDEP school guide.<sup>8</sup>

In 2005, the Safe at School Task Force was formed to create a long-range strategy to guide the Association's school advocacy efforts. The task force brings together top Association volunteers who are health care professionals, lawyers, school personnel, and parents.

## Adopting Contract Antidiscrimination Provisions

As a result of litigation against the City of San Antonio and the City of Philadelphia (cities in which the Association held its 2000 and 2001 annual meetings, bringing thousands of people and millions of dollars into the local economies), the Association developed Partners in Equality (PIE). PIE is a program through which the Association's business contracts contain a diabetes antidiscrimination provision.

The PIE language (Table 3) is now in hundreds of contracts involving millions of dollars and also extends to agreements with companies that donate money to the Association. It is now a standard clause in all of the Association's vendor and meeting contracts. The PIE program is designed to be prophylactic in preventing diabetes discrimination in return for the substantial economic benefit of doing business with the Association.

Today, PIE is well received and embraced by virtually all people and entities with which the Association does business. There is only one notable exception. In 2005, the UPS shipping company refused to sign the PIE agreement, at least without substantial alteration. UPS has a long history of discriminating against people with diabetes. After a series of negotiations with UPS on both altering the PIE language and improving company policies and practices toward people with diabetes, the Association determined that its mission and business interests were best served by working with a different vendor.

Including PIE language is now the only way the Association does business. The PIE program is a terrific example of how the Association's legal advocacy efforts focus and use the business clout of the Association to achieve significant benefits for people with diabetes in the workplace.

## TOOLS FOR DIABETES JUDICIAL LEGAL ADVOCACY

The Association uses a variety of tools to further its judicial legal advocacy efforts. These tools allow the Association to play different roles in court proceedings to help eliminate discrimination against people with diabetes.

## The Association as Amicus Curiae (Friend of the Court)

The function of an amicus curiae is to provide a court with educational information about a particular problem. The Association's efforts as amicus curiae provide courts with educational briefs regarding diabetes in the workplace. Amicus briefs educate both courts and employers about the medicine and science regarding dia-

#### Table 3. PIE Contract Language

"By signing this contract, [vendor] verifies that it is in compliance with all laws prohibiting discrimination against people with diabetes, including, but not limited to, the Americans with Disabilities Act, the Rehabilitation Act of 1973, and state and municipal antidiscrimination laws. [Vendor] verifies that it will not discriminate against a qualified individual with diabetes because of the person's diabetes, in regard to job application procedures, the hiring, advancement, or discharge of employees, employee compensation, job training, or other terms, conditions, and privileges of employment. [Vendor] further verifies that each person with diabetes, whether or not the person uses insulin, is eligible for any employment with the contractor for which he/she is otherwise qualified and that [vendor] does not have any rule or policy that automatically excludes a person with diabetes from employment in any position with [vendor]."

betes, including advances in how diabetes is managed. Increasingly, the Association's amicus briefs focus on explaining diabetes and diabetes management rather than on legal issues regarding employment rights and remedies.

The Association acts as an advocate for better and more opportunities for people with diabetes and for the safety of people with diabetes rather than as an advocate for any particular person or legal issue. Several key amicus efforts illustrate how this refined approach garnered positive results.

Kapche v. City of San Antonio

In Kapche, the Association, in conjunction with the Texas Employment Lawyers Association and DOJ, provided the court with persuasive information about how an individual who takes insulin can effectively and safely perform the job of a police officer. As a result of the Association's help, Jeff Kapche achieved a significant financial settlement and changed the hiring practices of one of the largest police departments in the country. Most importantly, the Kapche case eliminated one of the last blanket bans against people with diabetes who take insulin.

The *Kapche* struggle took > 8 years, including two different appeals to the U.S. Court of Appeals for the Fifth Circuit and two different Association amicus briefs. During the *Kapche* appeals, the Association was formally recognized as an authority on diabetes by being extensively quoted in the court's opinion in *Kapche I*<sup>20</sup> and by participating in oral argument of the case in *Kapche II*.<sup>21</sup> Never before was the Association quoted in an appellate court opinion or permitted to participate in an appellate court oral argument.

#### Frasier v. US Bancorp

In *Frasier*,<sup>22</sup> the Association, in conjunction with the AARP Foundation, helped achieve a significant victory on the issue of whether individuals with diabetes are covered by federal laws prohibiting discrimination against people with disabilities. Federal law requires an individual to establish that he or she has a disability, is regarded as having one, or has a record of a disability in order to be protected from even explicit discrimination on the basis of diabetes. In *Frasier*, the

Ninth Circuit Court of Appeals accepted that eating is a major life activity that can be looked at to see if it is substantially impaired by diabetes. The court determined that the issue of whether a diabetes treatment regimen was so demanding so as to impair eating was a question for a jury.

The *Frasier* case represents a significant evolution regarding the most effective way to present and win a case involving insulin-treated diabetes in the workplace. It included the Association's first moot court exercise for the attorney who argued the case.

#### Branham v. Snow

Branham v. Snow23 involved Gary Branham, a long-time Internal Revenue Service (IRS) worker who wanted to become an IRS special agent, a law enforcement position. In this case, the Seventh Circuit Court of Appeals decided that a person with tightly controlled type 1 diabetes may nonetheless qualify as having a disability under federal law because of his rigorous treatment regimen. When compared with an average person in the general population, Branham was significantly restricted in the manner in which he was required to eat to effectively treat his diabetes.

In *Branham*, for the first time, the Association presented in its amicus brief a chart that dramatically and graphically outlined at least 10 significant ways in which people with insulin-treated diabetes must do things not required of those without diabetes to safely and effectively manage their diabetes. This decision also firmly established that employers that claim that people with diabetes cannot do a given job bear the burden of showing that these individuals create a direct threat to themselves or others in that job.

Branham created a persuasive methodology that people with insulintreated diabetes can both have a disability and still be qualified to safely work in law enforcement—type jobs. An attorney member of the Association's legal advocacy committee took over the case at the appellate stage and for the subsequent jury trial. Not only did the jury return a substantial verdict for Branham, but the trial in this case produced a plethora of discovery and trial documents that

will be used in future diabetes cases.

#### Urban v. Dolgencorp

In *Urban*,<sup>24</sup> the Association appeared as amicus on rehearing of an opinion of the Fifth Circuit Court of Appeals that hindered people needing Family and Medical Leave Act benefits. The original opinion placed undue burdens on people with medical conditions such as diabetes, as well as their families, who need time off work because of such conditions. On rehearing, the court changed its mind and sent the case back to the trial court for further proceedings, ending the effect of the court's prior restrictive opinion.

#### Rodriguez v. Con Agra Grocery Products Company

In *Rodriguez*, <sup>25</sup> the Association, in a joint brief with AARP, Advocacy Inc., and the Coalition of Texans with Disabilities, and in conjunction with the EEOC, helped achieve a significant victory for a person with type 2 diabetes who was denied a production job because of a single urine test. In this case, the court not only reversed a decision for the employer but also granted the employee summary judgment, a significant and rare occurrence.

This case was important to stem a growing argument that diabetes is a "controllable condition" and that those who fail to achieve what an employer considers adequate control are not protected from discrimination. As the court in *Rodriguez* correctly determined, the only true issue is whether the individual is able to do the job in question based on an adequate individual assessment.

## The Association in Joint Amicus Curiae Briefs

Since 1999, the Association has appeared as amicus curiae in a variety of cases before the U.S. Supreme Court by partnering with others in presenting a joint amicus brief.<sup>26</sup> In this situation, the Association does not have responsibility for preparing and presenting an amicus brief but rather reviews, provides input, and joins with other organizations in filing a joint brief on particular legal issues. This approach allows the Association to participate as amicus curiae and to lend the weight of its authority in cases that do not directly involve dia-

betes but that will have a major impact on the course of disability discrimination law and thus on people with diabetes.

The Association also joins other disability rights organizations in matters of public importance that can affect all disabilities. In Little v. Tex. Dept. Crim. Justice,<sup>27</sup> the trial court held that a woman missing a leg was not protected by the disability discrimination law because she managed to live a somewhat normal life. The Association, concerned that highachieving people with disabilities might find themselves shut out of any protection, decided to appear as amicus in the Texas Supreme Court. The Association realized that the same arguments could be made against people with diabetes who, with determination and sacrifice, are successful in life, despite their disease. Together with other disability rights organizations, the Association filed an amicus brief that was cited in the court's opinion reversing the trial court and finding in favor of Little.

The Association as a Party Plaintiff Since 1999, the Association has agreed to become a named plaintiff in two class action lawsuits.

## People with diabetes in police custody

In Rosen v. City of Philadelphia, 28 the Association joined a class action for people with diabetes who were held in custody by Philadelphia and were denied adequate medical care. The Association joined the injunctive part of the case to obtain better diabetes management and treatment for people in custody. The significance of this involvement cannot be overstated. For the first time, the Association decided to undertake a major litigation effort for some of the most vulnerable people with diabetes in a restrictive environment under difficult conditions.

As a result of the Association's involvement, Philadelphia settled the injunctive portion of the case with a diabetes training, management, and treatment protocol and a lengthy monitoring period. The stipulated settlement required Philadelphia to take a number of more effective diabetes management steps as well as to undertake diabetes training of police employees. The efforts included hav-

ing appropriate food and medication available to people with diabetes, developing diabetes posters and a video on how police should identify and respond to individuals with diabetes, and instituting protocols to ensure that people with diabetes receive timely, appropriate care from health care professionals.

Additionally, the Association recruited health care professionals and police volunteers to inspect the custodial facilities and provide reports on the progress of diabetes management. As with other Association legal advocacy experiences, the efforts in this case led to efforts to create more uniformly effective and adaptable guidelines for use in custodial facilities nationwide.

#### Students with diabetes

In K.C. v. O'Connell,<sup>29</sup> the Association agreed to be a plaintiff in a case seeking better diabetes care for elementary and secondary students in California public schools. In partnership with Disability Rights Education & Defense Fund (DREDF),<sup>30</sup> the Association is seeking to require California to provide necessary diabetes care as set out in the Association position statement<sup>5</sup> and in the NDEP school guide.<sup>8</sup>

The genesis of the *K.C. v.* O'*Connell* case was the refusal of several named school districts to allow any school personnel to administer insulin to students who are unable to self-treat and the need to have trained school staff available at school and all school-related activities. This lawsuit, which is currently pending, will have far-reaching consequences in the state with the largest number of children with diabetes in public education.

# The Association as Legal Consultant A variety of private attorneys, governmental agencies, and private advocacy groups turn to the Association for medical, scientific, and legal advice

medical, scientific, and legal advice and input on cases involving diabetes issues. The range of this involvement is illustrated by the following cases.

#### Lawson v. CSX Transportation

In *Lawson*<sup>31</sup> the Association worked closely with the plaintiff's attorneys in shaping diabetes issues that resulted in a landmark decision to allow a person to become employed as a trainee for a train conductor position. This was the first court of appeals case to establish

coverage under federal disability law based on the limitations diabetes poses on the major life activity of eating and establishing coverage because the plaintiff had a "record of" a disability.

United States v. SFX Entertainment In SFX Entertainment<sup>32</sup> the Association worked closely with both the DOJ and SFX Entertainment, with the agreement of both, in a case involving access to diabetes supplies at concert venues. The Association provided medical expertise on the need for immediate access to supplies and the safety of performing diabetes care tasks in a concert environment. The settlement of this case created a protocol for allowing people with diabetes to carry necessary testing and treatment supplies into a concert venue, thus allowing for full participation of people with diabetes. Such a settlement involving both the federal government and the world's largest owner of concert venues is a persuasive model for other owners of places of public accommodation.

#### Referral Services for Diabetes Legal Advocacy

Anyone in the United States can call the Association's Call Center and request written information and the opportunity to talk to a lawyer about specific discrimination matters. The availability of this hotline service is widely publicized and has created a growing demand—now > 300 calls per month—reflecting the incredible need for legal advocacy help for the > 20 million Americans with diabetes and their families, coworkers, and friends. This service provides the Association with valuable insight into the real-world problems affecting people with diabetes. Individuals who contact the Association gain access to its Advocacy Attorney Network and Health Care Professionals Legal Advocacy Networks, described below.

#### INSTITUTIONALIZATION OF DIABETES LEGAL ADVOCACY EFFORTS

The Association's successful legal advocacy program requires various resources to organize and institutionalize its continuity and vitality.

The Association's Strategic Plan

Each year, the Association's Board of Directors reinforces its permanent commitment to a nationwide strategic plan that lists as an advocacy outcome: "End discrimination against people because of their diabetes." This is the genesis of the Association's legal advocacy efforts and creates the stimulus for budget allocations for legal advocacy efforts.

#### Task Force on Advocacy

As a result of the tremendous demand for advocacy, the Association appointed a task force to evaluate the effectiveness and needs of all its advocacy efforts, including legal advocacy. In May 2004, that task force issued a report to the Association that thoroughly reviewed all legal advocacy efforts and offered recommendations for continued efforts and budgetary requirements to achieve those efforts.<sup>33</sup>

This was the first time the Association's legal advocacy efforts were evaluated by the Association's most knowledgeable volunteers and staff. The task force report emphasized both the uniqueness and effectiveness of the Association's legal advocacy efforts and became a driver for additional financial resources dedicated to legal advocacy efforts.

**Expansion of Legal Advocacy Staff** In 1999, the Association hired a director of legal advocacy as the first employee dedicated exclusively to legal advocacy efforts. The Association now has six employees dedicated to legal advocacy, people who handle a variety of specific legal advocacy functions, and administrative staff to support those efforts (Table 4). The Association's support of this dramatic expansion of the staff side of legal advocacy reflects an appreciation of the success of legal advocacy as well as the growing need for increased efforts in a variety of areas.

Specialization of the Volunteer Effort To support the increasing demands for legal advocacy, the Association created a legal advocacy subcommittee and volunteer networks for attorneys and health care professionals.

#### Legal advocacy subcommittee

This subcommittee, which is a standing committee of the national advocacy committee, expanded during the past 6 years in two important ways: it

## Table 4. American Diabetes Association Legal Advocacy Staff

- Shereen Arent, Managing Director, Legal Advocacy
- Steve Bieringer, Manager, Legal Advocacy Major Projects
- Patricia Brouse, Specialist, Legal and Grassroots Advocacy
- Brian Dimmick, Associate Director, Staff Attorney
- Katie Hathaway, Manager, Legal Advocacy
- Crystal Jackson, Manager, Legal Advocacy

added health professionals and recruited legal experts in specific areas. The subcommittee now includes nine attorneys and two health care professionals. For health care professional help, the Association recruited two of the nation's leading experts in endocrinology and diabetes education. In legal specialty areas, the Association recruited lawyers with particular expertise in employment law, jail conditions, education law, appellate law, and class action law. This growth provided the Association with cutting-edge advice from experts recognized for their knowledge and experience in areas crucial to managing legal advocacy efforts.

#### Attorney advocacy network

To provide needed resources to the many people who contact the Association on discrimination matters, the Association created the Attorney Advocacy Network, which is made up of lawyers from across the country who have agreed to provide help in diabetes cases, either pro bono or in the regular course of their practices. This is an effort to connect people who call the Association with a lawyer in their geographic area who can discuss particular diabetes legal problems.

The Association does not specifically recommend an attorney but rather provides individuals with the names of attorneys who indicate an interest in talking to people with diabetes in particular problem areas in specific geographic locations. It is up to the people seeking legal assistance to make the attorney contacts and proceed accordingly. Also, network lawyers take on many key legal advo-

cacy tasks beyond individual advice or representation, including representing the Association as a plaintiff and as an amicus curiae, undertaking large and small research projects, and taking on key advocacy roles in legislative and regulatory initiatives.

Network attorneys, now numbering ~ 250, receive regular information and updates via e-mail. More than 60 of them participated in a 2-day educational seminar in October 2005, entitled "Fighting for Fairness: Ending Discrimination Against Students and Workers with Diabetes." Lawyers interested in joining this network should contact Steve Bieringer via e-mail at sbieringer@diabetes.org.

## Health professional advocacy network

In addition to the attorney network, the Association organized a health professional advocacy network composed of physicians, nurses, diabetes educators, and dietitians who provide expert consultation and advice regarding diabetes issues. Input from a health professional is needed to determine issues of work suitability, work capacity, reasonable accommodations, and the merits of a case before litigation.

This network provides support not only for the Association's judicial efforts, but also for all of its educational, regulatory, and legislative activities. Simply put, no diabetes discrimination case or legislative or policy initiative can be successful without the authoritative information supplied by qualified health care professionals. This network taps into the powerful scientific knowledge and expertise of the Association's professional membership.

The network now includes ~ 100 health care professionals. Those interested in joining the network should contact Steve Bieringer via e-mail at sbieringer@diabetes.org.

#### **CONCLUSION**

The Association's legal advocacy efforts roared into the 21st century with many significant accomplishments and the allocation of additional resources to meet an ever-increasing need. An old adage certainly applies to diabetes legal advocacy: if you build it, they will come. With the increase in the visibility of the Association's legal advocacy efforts, including increased awareness of its

success, more demands are being placed on the Association to help government, professional associations, employers, educators, employees, students, inmates, and a wide variety of people affected by diabetes with diabetes-related legal issues.

The future of diabetes legal advocacy requires a hand on the tiller to steer many diverse efforts, as well as an eye on the horizon to be able to respond to growing and changing needs.

#### References

<sup>1</sup>Greene M: The age of legal advocacy for diabetes. *Diabetes Spectrum* 12:214–221, 1999

<sup>2</sup>American Diabetes Association: Clinical practice recommendations 2006. *Diabetes Care* 29 (Suppl. 1):S1–S85 2006

<sup>3</sup>The Association publishes four professional journals with widespread circulation: *Diabetes* (original scientific research about diabetes), *Diabetes Care* (original human studies about diabetes treatment), *Clinical Diabetes* (information about state-of-the-art care for people with diabetes), and *Diabetes Spectrum* (review and original articles on clinical diabetes management).

<sup>4</sup>American Diabetes Association: Hypoglycemia and employment licensure (Position Statement). *Diabetes Care* 29 (Suppl. 1):S67, 2006

<sup>5</sup>American Diabetes Association: Diabetes care in the school and day care setting (Position Statement). *Diabetes Care* 29 (Suppl. 1):S49–S55, 2006

<sup>6</sup>American Diabetes Association: Diabetes management in correctional institutions (Position Statement). *Diabetes Care* 29 (Suppl. 1):S59–S66, 2006

<sup>7</sup>Gaddis v. Campbell., CV-03-T-390-N (USDC MD Al. 2004)

<sup>8</sup>U.S. Department of Health and Human Services: Helping the Student With Diabetes Succeed: A Guide for School Personnel [article online]. Washington, D.C., U.S. Department of Health and Human Services, 2003. Available from http://www.ndep.nih.gov/diabetes/pubs/ Youth\_SchoolGuide.pdf

<sup>9</sup>American Diabetes Association: Diabetes Care Tasks: What Key Personnel Need to Know [PowerPoint presentation online]. Available from www.diabetes.org/schooltraining

<sup>10</sup>Dickson M, Arent S: *Employment Considerations for People Who Have Diabetes*. New York, Cornell University, 2001

<sup>11</sup>NFPA 1582 Standard on Comprehensive Occupational Medical Program for Fire Departments (2003 Edition), section 6.18 and 9.6 Endocrine and Metabolic Disorders [article online], 2003. Available from http://www.nfpa.org/ aboutthecodes/AboutTheCodes.asp?DocNum=1 582

<sup>12</sup>NFPA Technical Committee Document Proposal Form for 1582 Standard revisions to section 6.18 and 9.6 [article online], 2004. Available from http://www.nfpa.org/about

thecodes/AboutTheCodes.asp?DocNum=1582

<sup>13</sup>ADA Advocacy Network legal materials bank [article online]. Available from www.diabetes.org/discrimination

<sup>14</sup>Discrimination based on diabetes [article online]. Available from www.diabetes.org/ attorneymaterials

<sup>15</sup>Rapp J, Arent S, Dimmick B, Jackson C: Legal rights of students with diabetes. Alexandria, Va., American Diabetes Association, 2005. Available online from http://www.diabetes.org/advocacyand-legalresources/attorneymaterials/ legalrights.jsp

<sup>16</sup>E.g., Federal Aviation Administration Pilots' Protocol, 14 C.F.R. § 67.401 and Fed. Reg. 226 at 39282 (11/21/96)

<sup>17</sup>49 U.S.C. 31.315 and 31.136(e); 49 C.F.R. 391.41(b)(3); 66 F.R. 39548 and 68 F.R. 5241

<sup>18</sup>Safe, Accountable Flexible, Efficient Transportation Equity Act: A Legacy for Users § 4129 (2005) F.R. 67777 (2005)

<sup>19</sup>American Diabetes Association: Safe at School campaign statement of principles [article online]. Available from www.diabetes.org/safeatschoolprinciples <sup>20</sup>176 F.3d 840 (5th Cir. 1999)

<sup>21</sup>304 F.2d 493 (5th Cir. 2002)

<sup>22</sup>342 F.3d 1032 (9th Cir. 2003)

23392 F.3d 896 (7th Cir. 2004)

<sup>24</sup>398 F.3d 699 (5th Cir. 2005)

<sup>25</sup>431 F.3d 204 (2005)

<sup>26</sup>E.g., Spector v. Norwegian Cruise Line, 125 S.Ct. 2169 (2005) (application of the Americans With Disabilities Act to foreign-flagged cruise ships in U.S. waters); Tennessee v. Lane, 541 U.S. 509 (2004) (Title II of the Americans with Disabilities Act applies to state to vindicate right of access to courts); Chevron USA v. Echazabal, 536 U.S. 73 (2002) (the nature and scope of the direct threat defense to employment discrimination); PGA Tour v. Martin, 532 U.S. 661 (2001) (reasonable accommodations in places of public accommodation)

<sup>27</sup>148 S.W. 3d 374 (Tex. 2004)

<sup>28</sup>Civil Action no. 2000-CV-764 (USDC ED Pa.) (2000)

<sup>29</sup>Case no. C 05 4077 (USDC ND Ca) (2005)

<sup>30</sup>Previously, the Association partnered with

DREDF in two day-care cases involving diabetes management issues for students. Stuthard v. Kinder Care Learning Centers, Case no. C2-96-0185 (USDC So. Ohio, 1996) and Davis v. LaPetite Academy, Case no. CIV 97-0083-PHX-SMM (USDC Ariz. 1997), both of which also involved the DOJ and both of which settled successfully.

<sup>31</sup>245 F.3d 916 (7th Cir. 2001)

<sup>32</sup>Consent Order and Final Judgment Civil no. 02-CV-1929 (USDC ED Pa, June 2003)

<sup>33</sup>American Diabetes Association Task Force on Advocacy: Report to the American Diabetes Association Executive Committee, 14 May 2004

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